

Code

Code of Good Practice in MS

EMSP - European MS Platform
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A CODE OF GOOD PRACTICE ON THE RIGHTS AND QUALITY OF LIFE OF PEOPLE AFFECTED BY MULTIPLE SCLEROSIS

BACKGROUND SUMMARY

In December 2003 the European Parliament approved a report based upon a petition submitted by a British person with Multiple Sclerosis, Louise McVay. This report was actively supported by the European Multiple Sclerosis Platform and all EU Multiple Sclerosis Societies. Health Departments in most member states of the Union provided information which was used to assist with the preparation of the report.

The contents of the report, presented by Parliament's Rapporteur Uma Aaltonen from Finland, and herself a person with MS, analysed the experiences of people with MS in Europe. It did so with regard to the type of support they were able to obtain from their respective health services, as well as in relation to their social and family environment, and in particular their employment prospects.

The report also emphasised the most significant characteristic of MS is that it affects people who are at the prime of their life (contrary to almost all other incapacitating diseases affecting people in similar numbers) at a time when most will have young families and considerable career prospects.

The report makes clear that according to Article 152 of the EC Treaty "Community action which shall complement national policies shall be directed towards improving public health....." It also makes reference to provisions in the Charter of Fundamental Rights on the rights of persons with disabilities.

Paragraph 1 of the substantive resolution adopted by Parliament urges the Ministers of Health of the European Union to develop a "Code of Best Practice" concerning MS patients.

This Draft "Code of Good Practice" has been drafted by the European Multiple Sclerosis Platform, with an input from all MS societies, and drawing on European Consensus and reference documents focusing on MS and the United Nations Convention on the Rights of Disabled People.

Since July 2008, translations of the "Code" are available via the relevant National MS Society in the following languages: Bulgarian, Croatian, Czech, Dutch, Estonian, Finnish, French, Greek, Hungarian, Icelandic, Italia, Lithuanian, Maltese, Norwegian, Polish, Portuguese, Romanian, Slovakian, Slovenian, Spanish, Swedish.

Contact and details: www.ms-in-europe.org

PREAMBLE

EC Treaty; Article 152.

1. ...“Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education.”

2.“The Community shall encourage cooperation between the Member States...Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1.”

“There are hundreds of thousands of MS sufferers in the UK and across Europe who are finding life a lot harder than me but I am a strong person and fight hard to get what I should rightfully receive, while others are not in a position to be like this”

Louise McVay before the Committee on Petitions, European Parliament. July 2003

Multiple Sclerosis (MS) is a complex, chronic, disabling disease. It affects twice as many women as men, and is usually first diagnosed between the ages of 20 and 40, at a critical stage in adult life with often considerable family and work responsibilities. An unpredictable and progressive disease, MS affects profoundly the quality of life of the person from the moment of diagnosis until the end of their life.

Although the impact of the disease varies with the type of MS, with the individual, and often from day-to-day, common symptoms could include fatigue, bladder and bowel disorders, vision problems, poor dexterity, spasticity, abnormal speech, swallowing disorders, sexual dysfunction, cognitive impairment, mobility problems, pain and depression.

Almost 500,000 people across the EU are directly affected, but of course the disease affects indirectly many more people who are close to them. To date, no cure has been found for MS.

There is highly robust scientific evidence and expert opinion of the very beneficial, indeed, critical effects of professional and high standard treatments, therapies and services on the quality of life of people affected by MS and their capacity to continue to contribute to society as workers, as consumers, as citizens. And from a purely cost benefit perspective, studies have demonstrated unequivocally that the investment this entails is significantly less than the negative economic and social consequences of mismanagement of multiple sclerosis.¹

¹ Kobelt, G., Lindgren, P., Smala, A., Rieckmann, P and the German Cost of MS Study Group. *Costs and Quality of Life in Multiple Sclerosis*. An observational study in Germany. *Health Economics in Prevention and Care* 2; 60-68, 2001.

Estimation of the cost of MS in Europe: Extrapolations from a multinational cost study P Sobocki, M Pugliatti, K Lauer and G Kobelt Flachenecker P, Rieckmann P. *Early Intervention in Multiple Sclerosis: Better Outcomes for Patients and Society?* *Drugs* 63: 1525-1532, 2003

Flachenecker P, Rieckmann P. Health outcomes in multiple sclerosis. *Curr. Opin. Neurol* 17: 257-261, 2004

Yet there is a huge disparity in the way in which people affected by MS are treated across the European Union, and consequently their quality of life. This is, in part, due to lack of awareness and information on evidence-based good practice in the field.

In a Europe that is built on fundamental values of equity, solidarity and human rights, it is extremely unjust that people should have access or not to crucial drugs, therapies and services purely in accordance with where they happen to live in the EU.

Hand in hand with the human factors relating to the management of multiple sclerosis, is the vital need to know more about MS as a disease, if we are really to make progress both in finding a cure, setting up effective prevention mechanisms and advancing MS management. There is much research work throughout Europe and this needs to be supported by strong political drive and effective coordination to move frontiers in this highly complex area.

Job retention, and the meaningful participation of people affected by MS at both macro and micro level in the decisions that affect them are two further areas that are instrumental to the health and quality of life of people affected by MS. These are also addressed in this Code of Good Practice.

The Code has been drawn up as a crucial follow up to a European Parliament Resolution² and report that identified the root causes of discrimination and inequality for EU citizens affected by MS and outlined a number of political and programme initiatives needed to redress this issue.

Once adopted by the European Health Council, this Code is targeted towards all stakeholders in the lives of people affected by MS, including policy makers and administrators, the medical profession, the corporate sector, volunteers, families, and of course, the person affected by MS.

The Code is a political instrument that outlines briefly the issues of fundamental importance to people affected by MS. It provides a practical framework that describes in general terms:

- ▶ The optimal approach in relation to treatments, therapies and services, research, employment, and empowerment of people affected by MS.
- ▶ It signposts core reference documents and materials that are endorsed by both the medical and patient community.
- ▶ It commits national governments and the European Commission to an independent monitoring system that will feed into the open method of coordination on public health.

² A5-0451/3003 European Parliament Resolution on Petition 842/2001 concerning the effects of discriminatory treatment afforded to persons with multiple sclerosis within the European Union

It is important to highlight that the scope of this Code does not address some of the broader accessibility challenges of relevance, not only to people affected by MS, but to the disability movement in general, as vital as this is. The Code focuses instead on the core issues relating specifically to rights and quality of life of people affected by MS.

Links between the Code of Good Practice and the UN Convention on the Rights of Persons with Disabilities.

The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted on 13 December 2006, and was opened for signature on 30 March 2007. The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

There are number of references in the UN Convention on the Rights of Disabled People, which supports and reinforces the European Code of Good Practice on the rights and quality of life of people affected by MS. The UN Convention, once ratified, is legally binding and relates to disabled people in general. The Code is not legally binding but is very specific to the rights and quality of life of people affected by MS, drawing on key policy developments and consensus papers in the field. In this respect it is clear that these instruments are highly complementary.

SOME FACTS

- ▶ On average, only 28% of people affected by MS in Europe have access to disease modifying drugs. In Poland this figure falls to 1%.
- ▶ In many countries of the European Union, there is a dire shortage of medical experts with specialist knowledge of MS. In the Republic of Ireland for example, there are only 14 neurologists throughout the country.
- ▶ In every EU member state, employment rates, and job retention rates among people affected by MS, despite stark evidence of the health benefits of remaining in work, are two to three times lower than the remainder of the population

GOOD PRACTICE IN FOUR KEY AREAS CRITICAL TO THE HEALTH QUALITY OF LIFE OF PEOPLE AFFECTED BY MS

Multiple Sclerosis recognises no borders: the needs of people affected by MS are comparable across national boundaries but will be addressed by health systems, which vary significantly in their organisation, funding and population distribution.

This section describes good practice in four key areas critical to the health and Quality of Life of People affected by MS.

- ▶ Equal rights and access to treatment, therapies and services in the management of Multiple Sclerosis
- ▶ A shared agenda in MS research
- ▶ Employment and Job retention
- ▶ Participation and Empowerment

"I just want to be me - a mother, an employee, a friend. I have tremendous will and all the knowledge and life experience I had before the diagnosis. I don't want MS to be central to who I am. I want to be able to deal with it with the right help and simply live my life"

Young woman affected by MS from Greece

1. Equal Rights and access to treatment, therapies and services in the management of Multiple Sclerosis

Equal treatment, non-discrimination and reasonable accommodation are now concepts enshrined in European Union law. For people with MS to remain active and engaged citizens they need access to high standard, appropriate treatments, therapies and services, to enable them to continue to participate and contribute to society on an equal basis.

It is important to highlight and recognise the extent, progression and diversity of the symptoms of multiple sclerosis, that range from mobility problems, to bladder and bowel disorders, to visual impairments. Some of the symptoms are visible, but others, like fatigue, are less palpable, leading sometimes to further alienation and isolation in today's fast moving society. Other symptoms such as sexual dysfunction or depression still carry stigma and taboo in some EU countries.

Some people are fortunate in their access to treatments, therapies and services, but the disparities between the types of care and support available are simply too great both within and between the member states of the European Union. This must be remedied by raising the level of care provided across the board bringing about equality of access as a clear objective. With free movement of persons recognised as a binding principle of the European Union, better provisions are needed to enable people affected by MS equal rights to treatment in all EU member states.

- ▶ The provision of a **clear, certain diagnosis as early as possible** by a neurologist with specialist knowledge in multiple sclerosis
- ▶ **Timely access to appropriate drugs** according to latest results of scientific research.
- ▶ **Referral** to a specialist neurological rehabilitation team, which should **recognise the varying and unique needs and expectations** of each person affected by MS.
- ▶ Inclusion within this **interdisciplinary team** of healthcare professionals from the following disciplines: neurology, rehabilitation medicine, nursing, physiotherapy, clinical psychology, social counselling, occupational therapy and speech therapy.
- ▶ The identification within the team of a single professional to act as a **focal point** or reference person for the person affected by MS, to guarantee **continuity of care and confidence**.
- ▶ Each individual affected by MS should be recognised as his or her **own MS Manager**.
- ▶ **Collaborative work** by the team, and other health professionals such as a dietician, together with the person affected by MS, to ensure **planning, problem assessment, and goal setting** in the long-term and short-term.
- ▶ The timely provision of **accessible information, informed advice and emotional support** from diagnosis onwards on the disease, its effect and potential impact on the individual, the family and the social environment as well as **self help education programmes for the individual and those who are close** to him / her.
- ▶ Because MS is unpredictable, particularly with regard to relapse occurrence and speed of disability progression, a **service** must have the capacity to **respond in a timely manner without excessive delay and bureaucracy**.
- ▶ Later, at the onset of greater impairment, the development of a **personalised symptom and disability management programme** co-developed by the person affected by MS and his/ her specialist team.
- ▶ At advance stages, **adequate and appropriate community care services** including home adaptations, assistive technologies and technical aids and supported housing to enhance mobility and independence.
- ▶ The right for people affected severely by MS to the right to **palliative care assessments and services**.

People affected by MS need

The brief summary above has been compiled from documents by world renowned medical and patient experts in the field of MS, and endorsed by both the medical community and European MS societies advocating for the rights and equal treatment of people affected by MS. These are referenced at the end of this Code and provide a comprehensive and detailed guide on each aspect outlined above and the education and resource implications.

Clearly, a prerequisite for many of the pointers highlighted above is trained and committed medical staff and an interdisciplinary patient-centred approach. This Code therefore calls for investment in the professional training of neurologists, specialised nursing staff and other health care practitioners in developing the necessary expertise and skills in the field of MS.

2. A shared MS research agenda

Research in the area of multiple sclerosis is highly complex, reflecting the compounding environmental, genetic and immunological factors linked to MS. Migration studies and studies relating to the onset and severity of infectious childhood diseases have indicated that co-causative environmental factors are operative long before the first MS manifestations, probably before puberty.

Despite significant investment in MS research in recent years, much further progress is needed in understanding the disease if we are to find a cure, and effective prevention mechanisms such as vaccines; advances in MS management must also be evidence-based through collaborative research and audit, also drawing from relevant research in non-MS areas.

Leading scientists in the field of MS have identified the following areas as research priorities

- ▶ Epidemiology (incidence, prevalence, migration, mortality)
- ▶ Genetics (predisposing factors)
- ▶ Clinical pathology (various disease types, diagnosis and prognosis),
- ▶ Therapy (prevention, disease modifying therapy, symptomatic treatment and rehabilitation, repair)

An acute problem in the field of MS research relates to lack of coordination. This Code calls for a **shared** MS research agenda and closer European scientific collaboration across the EU member states in the context of the EU research framework programmes in order to accelerate this progress, and to develop even more effective treatment of MS in all its forms: A transparent and workable strategy for scientific collaboration should constitute a criterion for EU and national funding, and a 'clearing' system through a credible independent global body like the Multiple Sclerosis International Federation should facilitate this process.

A shared MS research agenda should involve meaningfully people with MS in order to ensure that efforts are properly directed towards the real needs of persons affected by MS.

Research should also feed in more effectively to policy-making, and a concerted political effort is needed both to drive a shared research agenda and apply the evidence coherently in policy, strategy, and programming.

3. Employment and Job Retention

The onset of multiple sclerosis often occurs at the prime of life, when people have significant economic and social responsibilities. European wide survey and analysis reveal the positive psychological and physical benefits of job retention that can reduce the progression of the disease, yet many people affected by MS are forced to giving up work because of lack of support.

The Framework Directive on equal treatment in the work place³ is an important basis upon which to challenge this discrimination; the concept of 'reasonable accommodation' within the Directive should be interpreted to include flexible working, rest periods, the necessary work adaptations and a social protection safety net, that respond effectively to the symptoms of MS and ensure both access and dignity.

Much more focus is required, however to ensure that the Directive has the impact it could in relation to people affected by MS. This Code calls for information and awareness-raising programmes for employers, co-workers, and for those diagnosed with MS about the Directive, its scope and its potential both as an advocacy tool and to seek individual redress.

Alongside a strong legal framework, this code also calls for high quality vocational rehabilitation recognising its crucial role in identifying appropriate assistive equipment, environmental modifications, task re-structuring, task modification and support from co-workers or others as needed. It is important to identify and challenge work place barriers using creative solutions made possible through open communication with the employer.

³ Directive 2000/78/EC – A Framework Directive on Equal Treatment in the Work Place

4. Participation and empowerment of people affected by multiple sclerosis

Meaningful participation and empowerment of people affected by multiple sclerosis in the personal and political decisions that affect their lives is inherent to a genuinely rights based approach to multiple sclerosis.

Access to information is crucial. Nothing can empower a person with MS more than access to clear, concise information about their illness, the standards of drugs, treatments and services they have the right to expect, and the likely impact that this will have on their quality of life.

On a personal level, this also means access to treatments and services that⁴

- ▶ Recognise personal dignity
- ▶ Seek to maximise personal potential
- ▶ Enable people affected by MS to be fully involved and influence decisions about service provision
- ▶ Take account of the full range of physical, cognitive, emotional and social implications of being affected by MS
- ▶ Meet agreed European quality standards
- ▶ Are subject to continual evaluation and improvement
- ▶ Are accessible and timely,
- ▶ Are delivered by appropriately skilled and experienced professionals
- ▶ Are provided equitably and efficiently, irrespective of geography, organisational or professional boundaries.

This Code calls for user-led self-management courses for people affected by MS in order to enable them to acquire a full understanding of appropriate treatment, therapies and services, advocate for and co-manage as far as possible their own health.

This Code supports the right to independent living for people affected by MS, that requires the provision of timely and appropriate health and social care but also a fundamental respect for personal dignity and choice.

At macro level, national Multiple Sclerosis Societies are the representative voice of people affected by MS, and are entrusted by them to engage with governments, the medical community, the corporate world, and other members of civil society in advancing their interests and promoting their rights. This Code acknowledges in particular, the unique representative role of MS societies, as a partner in on going civil dialogue processes involving consultation and constructive critique from the perspective of users and their allies in striving for better quality of life for people affected by MS.

⁴From the Malta Declaration adopted by the European Multiple Sclerosis Platform in the framework of the European Year of People with Disabilities 2003

CONCLUSION

This Code outlines the key issues that govern the quality of life of people affected by MS. It gives a framework for good practice, however it is not exhaustive.

There is growing momentum in many areas relating to MS and in certain parts of Europe; in the research sphere, in the continuum of treatment, therapies and services, in breaking down the attitudinal and physical barriers that jeopardise the human rights and independence of people affected by MS. This Code will be pivotal in building on this momentum, uniting political will and practical know-how to achieve a better quality of life and brighter future for all people affected by MS in the European Union.

In itself however, it remains a statement of intent, an affirmation of commitment by the Member States of the European Union. Its strength will lie in the way the Code can be translated in to national policy and daily modus operandi in each country. To ensure that the Code has the impact it should, evaluation and benchmarking is crucial. This code should be underpinned by an independent monitoring system, using the recommendations within the Code as indicators to measure progress at national level and a biannual reporting system. This will in turn contribute on an ongoing basis to the European Commission's open method of coordination on public health. As highlighted in the EP Resolution on discrimination and people affected by MS, it will also be important to extend this coordination to the World Health Organization Regional Office in Copenhagen, and indeed WHO head office, to contribute to specific WHO initiatives on multiple sclerosis.

CORE REFERENCE DOCUMENTS

EU CONSENSUS DOCUMENTS AND REFERENCE PAPERS IN THE AREAS OF MS REFERRED TO IN THE CODE

► **The European Map of Multiple Sclerosis, www.europeanmapofms.org**

The European Map of MS database provides information and data on the epidemiology of MS and the availability and accessibility of resources for people with MS at country level. The contents of the database can be searched and illustrated through maps, charts or spreadsheets in the data query section. The whole database will be updated every four years. Data will also be gathered on an ongoing basis from countries that had not yet submitted data and new data will be gathered for new categories and sub categories as and when necessary, for example when a new treatment becomes available.

- ▶ **“Escalating Immunomodulatory Therapy of MS” (Consensus Paper) Updated version Sept. 2007**
 Leading Authors: Multiple Sclerosis Therapy Consensus Group (MSTCG) First draft developed by: Peter Rieckmann, Klaus V. Toyka, Ralf Gold, Hans-Peter Hartung, Reinhard Hohlfeld, Heinz Wiendl
 Current therapeutic recommendations, from the Updated and edited version 2007 of the original report 2006 (Nervenarzt 77:1506-18; 2006). Recent clinical studies in MS provide new data on the treatment of clinically isolated syndromes, on secondary progression, on direct comparison of immunomodulatory treatments and on dosing issues. All these studies have important implications for the optimised care of MS patients. The multiple sclerosis therapy consensus group (MSTCG) critically evaluated the available data and provides recommendations for the application of immunoprophylactic therapies.

- ▶ **Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe (European Multiple Sclerosis Platform and RIMS, Rehabilitation in Multiple Sclerosis)**
 Battaglia, Kesselring, Ketelaer, Thompson et al
 These recommendations are the result of intensive collaboration among foremost experts in Multiple Sclerosis Rehabilitation in Europe, and aim to contribute towards ensuring Europeans with MS have access to the best possible rehabilitation services at every stage of their illness.

- ▶ **Symptomatic Therapies Consensus Paper based on the German MS Society’s report “Mehr Lebensqualität ,Sympomatische Therapie bei MS”.** T Henze, KV Toyka
 Although there is a vast amount of scientific literature dealing with symptomatic treatment, high quality studies are still scarce. The MSTCG from Austria, Germany and Switzerland developed and published consensus guidelines based on the available evidence from clinical studies and on expert opinion collected and critically edited by a group of MS neurologists. The Consensus paper includes treatment guidelines for some of the most important MS symptoms such as motor function and coordination, cranial nerves, autonomic nervous system function e.g. bladder, bowel and sexual dysfunction, psychiatric and psychological problems, and pan and paroxysmal symptoms.

- ▶ **Position Paper Palliative care among people severely affected with multiple sclerosis**
 S Haffenden, I.Higginson, D.Pitschnau-Michel, R Voltz,
 This position paper based on recent studies underlines the need for patients severely affected by MS in Europe to have access to palliative care assessments and services.
 The Code also draws on the following document:

- ▶ **Principles to promote the quality of life of people with MS (International Federation of Multiple Sclerosis) Barnes et al**
 These 10 principles were designed to guide the development and evaluation of services that are provided by governments, for profit and not profit health and social services providers, employers and other organizations for people with MS.

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