

Inventory of Needs for People with MS.

Clinical care committee on social and vocational services

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Summary

After a brief introduction related to a short description of the disease, attention is focused on the degree of disability in MS and the allocation of services in Belgium.

According to the different stages of disability (recently diagnosed, limited disability, moderate disability and severely disability) the implementation of services and programmes of management and rehabilitation, as pointed out in a previous report "Standards of healthcare for people with MS » from the MS Society of UK and NI in collaboration with the National Hospital of Neurology and Neurosurgery London, are discussed.

In Belgium important steps have been achieved in services delivery for Persons with MS (PwMS), especially in the field of inpatient and outpatient care. The need of further development of more extensive networking with community services (transmural care) are highlighted.

Finally, the need of alleviating the physical, psychological and social burden of the MS caregiver has to be prioritized by the organization of more appropriate services. New perspectives of health care contributing to this aim should be elaborated.

MS, the disease

MS is a disease of the central nervous system (brain, brainstem and spinal cord). All related complaints in this disease, e.g. complaints about muscle strength, the bladder function, the sensibility or vision, are caused by demyelinating lesions and axonal loss of the brain or the spinal cord. MS occurs more often in women than in men. The proportion women/men is about 2:1.

Large demographic studies with identification of the number of people with MS per 100.000 inhabitants (prevalence rate) have demonstrated that MS has a nonrandom geographic distribution (1). Epidemiological studies in Flanders and Middle West-Europe (2) (Göttingen (D), Southampton (UK) show a prevalence rate between 89 to 96 MS patients per 100.000 inhabitants. On a worldwide basis, we are living in a "high risk zone". From there we can deduct that almost 9 to 10.000 people are suffering from MS in Belgium.

Degree of disability of the MS population

The degree of functional limitation (measurement of disability) strongly varies within the population. According to the epidemiological research conducted in Flanders and in The Netherlands, it is possible to divide MS population into 4 categories (3):

DSS 0-2

minimal disability

35%

DSS 3-5

moderate disability

24%

DSS 6-7

requiring assistance, use of wheelchair

23%

DSS 8-9

confined to chair, bed or totally helpless

18%

Although no incidental studies have been organized in Belgium, the incidence of MS can be estimated between the 3–5 cases a year per 100.000 inhabitants, i.e. 300 to 500 new MS cases a year. Registration in Denmark with the MS Registry (7) has shown that since the seventies the yearly amount of new cases has increased, especially among women.

From this it is obvious that in Belgium the more disabling form of MS is present in 41% of the population or in 4.100 patients and that 59% of people with MS or 5.900 patients are ambulatory without requiring any aid or rest for about 200 meters and remain functionally independent for everyday activities (ADL activities); some of them being unable to work a full day without special provisions.

General organization of services

Appropriate care and guidance programs emphasize the quality and size of the proposed services in which the person with MS and his family are central and the structures have to be adapted to the need of specialized and multidisciplinary care.

Management and rehabilitation have the intention to influence the course of the illness, possibly to reduce the progression and its consequences and to relieve and limit the resulting impairment, disability and handicap (loss of participation in social life).

MS is a disease which not only affects the patient, but also, in a very intense way, his immediate environment. These persons therefore also have to be involved in the management and rehabilitation programmes.

In a chronic and unpredictable illness such as MS adapted care can only be efficient if all participating partners are really involved in the caring program.

Networking in all its forms has to be developed between all partners, professional (formal care) and non-professional (informal care) in the treatment of MS in Belgium.

On the one hand this functional binding guarantees the continuity of care and on the other hand it determines the mutual collaboration between home and home services, caring in extramural and intramural. More outpatient clinics, accommodation and adapted forms of living for neurological patients have to be created.

Working as a team with the home front within the "Samenwerkingsinitiatieven in de Thuiszorg" (SIT's) – ("Collaboration Initiatives in Home Care") - has a special place here.

For every patient, a detailed medical and social file has to be made up which will specify the medical, care and rehabilitation elements, with imposed registration of minimal clinical data (MGK), minimal nursing data (MVG) and minimal rehabilitation data (MRG).

For the case manager/coordinator on the one hand and the authority (social security services) on the other hand the parameters are followed up related to the clinical evolution and the given treatment by different intra- or extramural services.

Specific questions about care and adapted care programmes

Depending on the clinical stage of the disease and the degree of disability, services have to be adapted to standards of health care. The development of these standards (6) was undertaken by the MS Society of GB and NI in collaboration with the National Hospital of Neurology and Neurosurgery, London.

Our intention was to evaluate how these standards were implemented through special services and management programmes in Belgium according to the need of 4 different categories of MS patients:

The recently diagnosed MS patient (DSS 0-2)

The MS patient with moderate disability (DSS 3-5)

The severely disabled MS patient (DSS 6-7)

The very severely disabled MS patient (DSS 8-9)

I. The recently diagnosed MS patient.

During the first stage of the disease the MS patient and his family are confronted with the first symptoms of the disease and generally show a minimal limitation in their functional abilities (DSS 0-2).

Key themes are:

- provision of a clear and certain diagnosis,
- support including counselling at the time of diagnosis,
- access to information about the disease, its affects and potential impact on the individual (micro), the family (meso) and the social environment (macro-level),
- continuing education to enable knowledge and experience of life with MS to be gained from professionals and others affected by MS

The diagnostic optimization occurs in a hospital that possesses, in complement of the necessary clinical expertise, a specialized laboratory of neuro-immunology, a service of clinical neurophysiology and a service of medical X-rays (MRI).

It is always difficult to deal with and to accept the diagnosis.

Even if we now know a more favourable course of the disease with better perspectives and possibilities of treatment than more or less ten years ago, MS is still an illness with unknown causes and thus no appropriate or efficient treatment. The fear and uncertainty about the course of the

disease, the feelings of powerlessness, of sorrow, revolt and resignation come and go. This problematic nature can only be helped sufficiently by a specialized MS team.

early guidance : at this stage, it is essential, though it is very often forgotten. This consists of a discussion about the diagnosis, the necessary information about MS and the physical, psychological and social consequences of the illness. Aspects such as stress-treatment, accepting the illness, employment and spatial accommodation at home and at work have a very special place here. This problem can not be handled by the family doctor or the neurologist alone. The hospitals taking responsibility for the treatment of these patients have to organize an MS Clinic, i.e. they have to supply next to the neurological service, the collaboration of a rehabilitation team specialized in MS (neurologist with special competence in rehabilitation, MS nurse, psychologist, social worker, occupational therapist and physiotherapist).

In Belgium a limited number of additional MS Clinics, or as they say in The Netherlands "MS Steunpunten" – ("MS Support Centres") – need to be created. Besides strict medical help they provide information, guidance and support. This is possible within a network where staff members with knowledge and expertise affiliated to a specialized MS rehabilitation service are working part time in an MS Clinic. The network will enable to pass over information between the MS Clinic and the community services. It is the responsibility of the care manager/co-ordinator on the one hand and the authority on the other hand, to make sure that a certain amount of parameters are followed related to the clinical evolution and the treatment given by the various intra- and extramural services.

In Flanders, a education and counselling programme, the "MS School for early MS patients and their partner", is organized in collaboration with the MS Society. This initiative is presently limited to more or less 40 MS patients and their partners a year which is not sufficient considering there is a new population of 300 to 500 new MS patients in Belgium a year.

It would be ideal at this stage to introduce – such as in some Scandinavian countries – an "Adaptation Training" program (4) of ten days in which all early MS patients can obtain more knowledge of and guidance in their illness.

early treatment : this has to be started as soon as possible. Especially immuno-modulation and in some patients immuno-suppression are very useful to influence the natural course of MS. Recent studies have clearly shown the importance of early therapy with immuno-modulation, not only to limit the inflammatory demyelinating "plaques" but also the progressive axonal loss.

Specialized centres where clinical scientific studies about this type of therapy occur, are very well indicated here. In Belgium different university and general hospitals and 3 specialized MS Rehabilitation hospitals are delivering these services.

II. The MS patient with moderate disability (DSS 3-5)

In this second stage, in which the patient experiences the illness as minimal or average, MS patients live the longest. According to the form and the course of the illness, the degree of ability to manage oneself is more or less limited here : "moderate disability" (DSS 3-5).

This stage is, for those who know a relapse remitting course of the illness, often important in the first years after the diagnosis and for an important minority of people this stage lasts for the rest of their future life. These people form a still active, good social and family and partly professionally integrated part of the patients.

For the early stage of the illness it is advisable that the MS patient is treated and followed up by a MS Clinic.

Key themes are :

- continuity in service provision
- provision of support and informed advice about relationships, employment, symptoms and impairment, housing and financial planning
- access to appropriate treatment and management options

Next to the immuno-modulation and immuno-suppression therapy a lot of attention goes to guidance and following up. Guidance and tracking related to employment for persons with MS (PwMS) in Belgium delivered under the heading called Arbeidstrajectbegeleiding (A.T.B.), application of work improving regulations, family counselling and energy management are all very important in this respect. Although a great number of these measures are specified in the Belgian legislation more efforts should be accomplished to facilitate their implementation.

Because after each new set back there is a repeat exploration of the possibilities of future life, the mourning process is very relevant. Feelings of sorrow, anger and fury are experienced. The partner, members of the family and children are also confronted with it.

People in this stage can even show a greater need of information and care. Many people with multiple sclerosis must learn to be very creative with their energy. This requires some time and some understanding from the family, friends and relations, but above all from the MS patient himself.

III. The severely disabled MS patient (DSS 6-7)

In the third stage, characterized by a more developed disability, there are more important impairments and a great variety of secondary complications. Relapses and remissions determine the future evolution and in the long term disabilities accumulate.

The medical, psychological, social consequences and complications require a multidisciplinary approach aiming to the possible reduction of symptoms, disability, handicap and the improvement in the quality of life.

The adaptation process, such as learning to cope with increasing limitations and disability, as well as learning to live with outside assistance is for many MS patients a difficult task.

The way in which the adaptation comes through is different from one person to another, but always aims to control uncertainty, dependency and declination of physical and mental skills.

It is important to highlight there is still need for discussion and that attention is given, not only to medical aspects, but also to social and society problems of the direct environment of the person with MS (the carer).

The key themes are:

- responsiveness to need in relation to significant changes in ability and accrued impairments
- access to and the location of professional services
- access to multidisciplinary expertise in symptom and disability management and treatment
- communication and co-ordination between service providers and care agencies
- empowerment of people with MS and their carers to enable them to take a partnership role in the disease management and treatment

In Belgium the treatment is delivered at home or at an outpatient clinic. After an acute stage of progression or any complications, the patient can be hospitalised for 3 or 4 weeks with an individually adapted rehabilitation programme, aiming at social and family integration.

For many PwMS outpatient treatment is needed in which remaining in the community and social integration are central.

For more serious physical and sometimes cognitive decline intense treatment and guidance is best given at a specialized hospital or clinic where more rehabilitation staff members and technical means are available.

If these patients stay in a rehabilitation hospital for a long time (5), the monthly cost for a patient increases to 1.300 EURO. Therefore other forms of accommodation are preferable for this type of patient, preferably at home somehow with intensive assistance. The development of ambulant rehabilitation surely contributes to a longer socio-family integration, a better quality of life and a cost efficient treatment.

Except for regular home care which is available for nursing, physiotherapy, medical surveillance and familial help, there is in Flanders – following the example of The Netherlands and the Scandinavian countries – the possibility for selected aid-dependent people to receive a personal assistance budget (PAB). This service offers to the disabled the possibility to freely buy the needed services on the free market. Learning from the experience in The Netherlands and the Scandinavian countries, we know that many users, if everything is well organized, are very satisfied with the system which allows them to organize help independently and allows them to make dates about time and nature of the help.

The PAB system gives people, especially with MS, a greater freedom by letting them look for helpers that fit their own circumstances and it is a plus on top of the regular help of an institution. Presently it is considered by the government if in the near future the PAB could also include adapted technical aid devices.

When the body functions begin to fail, one has to call upon aid appliances in order to be able to function as independently as possible and not be dependent on the often to limited help that exists. One thinks here of a social and/or medical personal alarm, a walking frame, a wheelchair, a specific

working chair, a computer, etc. Some of these can be asked for at the "Ziekenfonds" – ("National Health Service") - or at the "Fonds voor Sociale Integratie van Personen met een Handicap" - ("The Fund for Social Integration of the Disabled").

Asking for aid appliances can, with the well-founded advice of a multidisciplinary team (MDT), often be a help to an adequate supply. Such a team is able to give good advice about stress at work, home adaptation, work and (re)training, home adaptation etc.

In Belgium poor accessibility of some official buildings and of public transport result in the fact that some people are no longer able to stay in the social-professional circuit. Major efforts remain to be accomplished.

Accessibility to employment could be improved by an adapted and flexible timetable, more extensive vocational rehabilitation programmes and adaptations of social legislation facilitating professional reintegration.

Europe should vote as in the U.S. (Americans With Disabilities Act- ADA) (14) for the application of a special law prohibiting discrimination on the basis of disability in employment, state and local government services, transportation provided by public and private entities.

Home adaptation or the exact use of aid appliances also help people to become more independent. In adapted houses one can, eventually with the family, the disabled may benefit from ADL-help or 24/24 h. personal assistance (personel available in stand by to help the patient for a ADL activity). Apart from this, the PwMS uses home help for caring, nursing or domestic help and surveillance. Only a few can ask for a 24 hour service of ADL assistance. This service is still insufficiently elaborated and this shortness of provision can lead to unnecessary institutionalisation for some patients.

As part of the legislation, the authority can reduce barriers and improve integration so that a point of departure as equal as possible should be created for everybody in society, even if one uses a wheelchair for instance or has functional limitations. The standards rules of the United Nations are a good basis to reach this aim.

To many people with MS, having this illness means a financial decline, especially to those who do not have a good work disability insurance and therefore get a minimal allowance. For people who have never worked this means that they are dependent on this minimal allowance for the rest of their lives. For married women it can mean being completely dependent on their husband.

People with reduced income (benefiting only from a disability allowance) but also other patients may have financial difficulties because of the still remaining many personal financial contributions. One has to think here about the accumulated costs of the home adaptation, aid adaptation, (adapted) transport, medication, home care, hospital costs, etc. were reimbursement is only partial.

IV. The very severely disabled MS patient (DSS 8-9)

The fourth stage, determined by severe disability, is characterized by a broad range of complex needs of the patient, important involvement of the family in taking care and the community.

On the Kurtzke scale this patient is situated in the group of patients with a DSS 8 and 9, which means that he is dependent on mobility and for most ADL activities and thus needs a lot of support, even somewhat constant supervision. Here, therapy is most often limited to treatment and/or preventing secondary complications and reactivation.

This stage often requires mobilization of the services of several institutions, professionals, volunteer helpers and others, depending on whether the person lives at home or in an institution. In this stage the need of assistance from professionals (formal care), helpers and family (informal care) is very high.

The key themes are :

- provision of appropriate respite care and short breaks for both the carer and PwMS,
- provision of appropriate long term facilities
- access to information about support services and community care resources
- expertise in caring for people severely disabled with MS
- co-ordination of all services
- adequate and appropriate community care services including home adaptations, mobility equipment and aids, health services
- transport and community mobility facilities
- appropriate and knowledgeable palliative care.

These patients are in need of household help, care and nursing. From research in this field (5,11) we know that an important part of the care (more than 80%) is being done by volunteer carers. There is a danger that volunteers get tired, can not have a personal life and sooner or later even become dependent on help. Because of the great need for constant care some relations can also break down. How a volunteer carer can be relieved and can live his own life should always be analysed.

In Belgium we have to state here that "day centers" (adapted structures where heavy neurological patients can benefit from surveillance and assistance over the day, permitting to the carer to work or to have at least 4 h. a day of free personal time) are clearly missing and that is why people are too soon sent to an institutionalised department. In the area of North Brabant e.g. there is no day care centre at all for physically disabled people; in other areas, there are only a few opportunities available with adapted time table for neurological patients.

Regularly the severely disabled PwMS need to be sent to an institution for treatment of medical and/or psycho-social problems. It is mostly only an intermittent but regular admission into a specialized long term hospital or nursing home (1 or 2 times a year) that offers some relief and enables further home treatment.

If the need for caring and nursing is too high, home care may no longer be able to answer the need for care and other options of adapted care structure or home care form has to be looked for.

Residential homes for aging people are only an adapted solution for a minority of these patients because of the limited amount of staff members and non-corresponding age of the inhabitants of these services and the younger MS population.

Some people can be sent to a surrogate family home or a nursing home. There are some waiting lists for this. In the daily reality, in Belgium this situation leads to a long stay in a long term hospital.

Research data (5) concerning the use of professional help shows that for these severely disabled patients the costs are a strong determining element in the choice between home care on the one hand and admission into a nursing home or a long term hospital on the other hand.

More than 60% of type 4 patients (DSS 8-9) are hospitalised for about 53 days a year. The average cost a year of the care per patient for this group is strongly divergent : at home, in a long term hospital or in a residential home this cost amounts respectively to 8.000, 48.000 and 26.000 EURO.

These data indicate once more and on a strictly economical basis how economical home caring and treatment is opposed to a hospitalisation. These data also confirm how physical, psychological and social load and financial pressure is exerted on a partner or on a family member taking care of the patient at home. Supporting home care and alleviating the burden of the carer would certainly contribute to a longer home stay and a better quality of life of the PwMS and his family.

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References

- (1) Multiple Sclerosis. Paty D.W. and Ebers G.C. Contemporary Neurology Series, Davis Company, Philadelphia 1997 p. 1-572.
- (2) Prevalence of Multiple Sclerosis in Flanders, Belgium. van Ooteghem P. and coll. Neuroepidemiology 1994;13:222-225.
- (3) Epidemiologische aspecten van multiple sclerose. Minderhoud J. and coll. Tijdschrift voor Sociale Gezondheidszorg 1985;63:64-72.
- (4) 25 years of experience in adaptation training in MS. Ruutiainen J. In : Miscellaneous topics in MS. Ketelaer P. and Battaglia M., A.I.S.M. Genova, Italy, 1996;8:71-78.
- (5) Utilisation and cost of professional care and assistance according to disability of patients with multiple sclerosis in Flanders. Carton H. and coll. J Neurol Neurosurg Psychiatry 1998;64:444-450.
- (6) People with MS in long-term care. Good practice guidelines for service providers. Multiple Sclerosis Society and Leonard Cheshire, MS Society of Great Britain and Northern Ireland, 25 Effie Road, Fulham London SW6 1EE, 1997;1-20.
- (7) The Danish Multiple Sclerosis Registry : a 50 year follow-up. N.Koch-Henriksen Multiple Sclerosis 1999;5:293-296.
- (8) Integrated care pathways in multiple sclerosis rehabilitation : completing the audit cycle. Rossiter DA and coll. Multiple Sclerosis 1998;4:85-89.
- (9) The Multiple Sclerosis Functional Composite measure (MSFC) : an integrated approach to MS clinical outcome assessment. Multiple Sclerosis 1999;5:244-250.
- (10) Standards of healthcare for people with MS. Jenny Freeman, Jane Johnson, Sarah Rollinson, Jan Hatch and Alan Thompson; Multiple Sclerosis Society and National Hospital for Neurology and Neurosurgery, Sept. 1997 p.1-11.
- (11) Multiple Sclerose. Minderhoud J.M. Bohn Stafleu Van Loghum, 1999 p.1-277.
- (12) A questionnaire assessment of unmet needs for rehabilitation services : results of a pilot survey in five European countries. Kersten P, McLellan DL, Gross-Paju K, Grigoriadis N, Bencivenga R, Beneton C, Charlier M, Ketelaer P, Thompson AJ. Clinical Rehabilitation 2000;14:42-49.
- (13) A problem-oriented approach to multiple sclerosis. Ketelaer P, Prosiegel M, Battaglia M and Messmer-Uccelli M. Acco Leuven/Amersfoort 1997 p.1-380.
- (14) Understanding the Americans With Disabilities Act. Help Wanted, Job Opportunities (Tittle I) and Access State and Local Government (Tittle II). Eastern Paralyzed Veterans Association, 75-20 Astoria Blvd., Jackson Heights, New York 11370-1177.