

Talking About Communication in Multiple Sclerosis

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This booklet has been compiled by the Special Interest Group (SIG) on Communication and Swallowing of Rehabilitation in Multiple Sclerosis (RIMS) and is addressed to people with MS, their relatives, caregivers and health professionals, with the aim of providing information and guidance for the daily management of their difficulties.

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Notes

1 | What is communication?

Language is the main feature that distinguishes human beings from animals. Our central nervous system (CNS) can process experiences, information, intentions, attitudes, thoughts, feelings and sensations and turn them into words, even gestures and glances, which are intelligible to our interlocutors. The absence of communication leads to isolation.

What we think and feel and do, the places we go to, the people we are with... All these are factors which motivate us to communicate, which feed the messages we convey.

Communication is a complex phenomenon in which many things are involved, such as comprehension of what other people say and wish to express, the intention and the goal of what we say, the content of our message and its utterance or motor execution.

Multiple sclerosis can, to a greater or lesser extent, cause disturbances in communication.

2 | How can communication be affected in MS?

Communication is fundamental to all levels of daily activity and effective communication is necessary for the maintenance of a positive quality of life and psychosocial well-being. Even the most subtle communication impairment can influence the success with which an individual achieves his or her occupational, personal and interpersonal goals. Because the onset of MS typically occurs in early adulthood and the disease course is most often protracted, some patients with MS will develop and have to cope with communicative difficulties for the greater part of their adult lives. In addition, the ability of persons with MS to communicate effectively becomes increasingly necessary if they lose motor control and

progressively become more physically dependent on others.

As has been mentioned in section 1, communication is a complex phenomenon which involves many different domains. Consequently, communication problems can occur due to cognitive, motor and even behavioural or emotional disturbances.

Impairment of speech and voice

“My voice is lower than before, my voice gets lower and lower when I keep speaking, some people think I am drunk when I speak, I am slow speaking, I cannot pronounce difficult words, my tongue doesn’t obey me”

Speech is produced by a co-operation of different organs: lungs, glottis (with vocal cords) and articulation tract (mouth and nose cavity). Thus, speaking involves different mechanisms: breathing, voice production, resonance and articulation. Air pressure from the lungs creates a flow of air through the trachea, larynx and pharynx. When the vocal folds in the larynx are tensed, the airflow causes them to vibrate, producing voiced sound. Voiced sound is amplified and modified by the resonators (the throat, oral cavity and nasal cavity). Depending on the positions of the various articulators (jaw, tongue, soft palate, and lips), different speech sounds are produced.

Production of utterances with correct pronunciation, velocity and intonation requires great agility and co-ordination of respiratory, laryngeal and articulatory movements.

Sometimes neurological lesions alter mechanisms of speech and produce a speech disorder called dysarthria. Dysarthria is the speech disorder caused by weakness, slowing, incoordination or altered muscle tone in the respiratory, laryngeal and articulatory muscles.

People suffering from speech disturbances may have several symptoms such as slow or imprecise articulation, voice difficulties, or production of shorter sentences, for example. Generally, speech intelligibility is only slightly affected in MS and only causes problems in certain situations, such as noisy environments or with

people who can't hear well, but sometimes the disturbance can be serious. In extreme cases dysarthria can prevent oral communication and is then called anarthria.

The main symptoms of speech disturbances in MS are:

- **Imprecise articulation (dysarthria)**
Speech can be slow and slurred, with imprecise vowels and consonants, sudden breakdowns or excessive length of sounds. These difficulties are caused by slowness and weakness of tongue movements, and to a lesser extent, by difficulties related with movement of lips and jaw.
- **Voice abnormalities (dysphonia)**
There are different types of voice disturbances: harshness, breathiness, hoarseness and a strained-strangled voice. The voice intensity may be low and decrease with fatigue. In some cases the person can produce only short utterances. These disturbances are caused by abnormalities of breathing and of the laryngeal system. Deficits in breathing may consist of poor breath support and lack of breath control for speech. Deficits in the laryngeal system may be caused by hyper- or hypofunction. Sometimes the voice has an excessive nasal resonance.
- **Abnormal speech melody (dysprosody)**
The person with MS (PwMS) may show prosodic disturbances, such as slowness or excessive velocity; poor or excessive pitch variation; and excessive variation of loudness. These disturbances are caused by reduced breathing control, by laryngeal and articulatory dysfunction or by poor co-ordination between these components.

Sometimes people with MS do not have noticeable speech difficulties, but deficits of some of their components, such as tongue movement capacity or respiratory and phonatory function, appear early.

Impairment of cognition and high-level language functions

Both oral and written communication are highly demanding cognitive tasks. Quick word finding abilities and effective language integration and processing capacity are necessary to be competent in these tasks. Communication also requires the ability to remember and relate information, to draw conclusions and to express them in words and structured sentences. Moreover, initiative, cognitive flexibility and behaviour appropriateness are necessary for pragmatic competence in this domain, which means competence in social communication.

Attention, speed of information processing, memory, executive functions*, high-level language functions and visuospatial perception are the most frequently impaired cognitive domains. All these disturbances can affect the ability to achieve effective communication.

Hence, patients with MS may encounter what has been termed “cognitive-communication disorders”. The affected person may have difficulty comprehending subtlety in language, integrating spoken or written information, drawing conclusions or giving coherence to narrative.

Lack of self-awareness of cognitive deficits is also common and usually overlooked. It can make it difficult to use appropriate strategies and techniques to optimise communication.

The linguistic disturbances most often associated with MS are:

- **Word-finding disturbances**

“I don’t say exactly what I want to say, I know what I want to say but the word doesn’t come, words are so difficult to find that I lose my turn in conversation, so I prefer to keep quiet”.

For some PwMS it can be difficult to name a picture or to find words beginning with a certain letter or belonging to a certain family (e.g. animals). Sometimes this can be due to perceptual difficulties (in the case of naming a picture)

* Executive functions: cognitive abilities which allow initiation, control and regulation of goal-directed behaviours.

but more often it is due to difficulty finding the appropriate word, something that anyone can experience but happening more often in this case.

In spontaneous speech these word-finding difficulties are reflected in inappropriate pauses and use of inexact words and may, indirectly, be the cause of a decrease in verbal initiative.

- **Comprehension disturbances**

“I listen to the news, but I can’t remember what they say”

Although massive disturbances of comprehension are not normally found in PwMS, they can have difficulty understanding messages if these are long or complex. These difficulties are probably related to slowed information processing, with difficulty paying attention and difficulty remembering, integrating, organising and analysing the contents while listening or reading.

- **Verbal conceptual reasoning**

Communication often requires the use of verbal conceptual reasoning, flexibility, planning and problem-solving abilities. These functions can be impaired in PwMS. Consequently they can have difficulty understanding jokes, metaphors, ambiguous sentences or explaining complex concepts, orally or in writing.

- **Sentence construction**

PwMS can have a tendency to produce sentences that are awkward, incomplete and inconsistent. This may happen because the words are not exactly appropriate, because there are subtle errors in the syntactical construction or because they are used in a way which is not appropriate for the situation (e.g. too formal or too informal, telling facts which are not relevant for the situation, etc.).

- **Discourse: explaining, arguing, conversing**
 “I lose my idea when I am speaking, I cannot explain myself”.
 Oral or written discourse requires a high degree of cognitive-linguistic interchange. Due to the mentioned difficulties in using verbal conceptual reasoning, in memory, in verbal expression and in planning, among others, the explanatory abilities of PwMS are sometimes poor or confused. They may fail to provide essential information and may have a tendency to repeat information.
 Pragmatic factors also play a role in social conversation. On the one hand, difficulty processing the inferred information conveyed by facial expressions, physical distance, body posture and physical setting can contribute to the narrative disturbances in MS. On the other hand, a failure to take the listener’s point of view may worsen the abilities of PwMS to see the communicative needs of a situation. When these abilities are disturbed, the person is less competent in conversation.

Communication disturbances in daily life

At this point, it should not be surprising that people with MS and/or their relatives complain about communication difficulties. As we have seen, these troubles are sometimes caused by motor disturbances and sometimes by cognitive, pragmatic and, as will be described in section 3, by behavioural or emotional factors and by fatigue. Very often several of these factors at once are involved in the communicative disturbances of PwMS.

The impact of these problems on daily life is high and can lead to isolation and to decrease of the quality of life and of the levels of activity and participation in work and social life. As a consequence, they can have a negative feedback on the emotional state of the person affected and of the people around him/her.

Reduction of engagement in satisfactory activities and of social participation also involves a decrease in communication: when there is a lack of interesting activities, there is less motivation and that means less communication.

These are some of the situations which can be disturbed within the communication profile of PwMS:

- **Verbal initiative**

“My husband speaks less than he used to I have nothing interesting to tell”

Some PwMS speak less than before and take less initiative in conversations. Sometimes sentences become short and in very severe cases this lack of initiative can even lead to difficulties expressing urgent basic needs.

- **Participation in conversation**

“I can’t follow conversations, I can’t find my turn in conversations, it’s hard for me to speak on the phone, I am slow speaking, I prefer to keep quiet because it takes too long to tell things, it’s difficult for me to follow a conversation in a noisy place, with many people”

Conversation is a complex activity which requires the ability to pay attention without being distracted by the surrounding noises, to quickly understand the verbal and non-verbal messages from the other people, to catch their intentions, to follow when topics change, to remember what has been said, to find one’s turn to speak, to formulate messages appropriately, to speak loud enough to be heard, to pronounce words clearly and many other things. Certain situations, such as speaking with people one does not know, with several people at the same time, in noisy places or about new topics, can make participation in conversations still more difficult. For some PwMS it can be difficult to remember people’s names. Speaking on the telephone may be another difficult situation.

For some PwMS it is especially difficult to speak in depth about one topic, to explain a fact or a film and to give detailed information or instructions. It may also be difficult for them to express more differentiated opinions and to be flexible in their point of view, taking into account the others' points of view.

- **Following films, news and some TV programmes**

This activity can be made difficult by factors such as the speed of speech, the amount of information to be processed, the complexity of verbal and visual language or the complexity of a film plot.

- **Reading**

"I lose the thread when reading, I can't remember what I have already read when I pick up the book again"

Reading can be difficult because of visual and disturbances. Moreover, cognitive disturbances may affect complex reading tasks such as reading newspapers or novels.

- **Writing**

"My handwriting is bad"

On the one hand ataxia or lack of strength in the hands and on the other hand cognitive and linguistic impairments can interfere with several writing activities such as signing, taking notes, using a notebook, or more complex writing activities.

- **Using the computer**

The computer provides many patients with an important tool for entertainment, access to information and communication through games, internet and email. The computer can also be a useful resource for writing for those people who cannot write by hand. For some PwMS it can be dif-

difficult to use the computer because of motor, visual and/or cognitive impairments; however, there are many resources for adapting access to the computer.

- **Participation in rehabilitation programmes**
In addition to the impact on every day life, cognitive-communication impairment in PwMS may also affect neurorehabilitation. Therefore, cognitive-communication intervention is crucial not only for the improvement of cognitive performance per se, but also for the success of the whole neurorehabilitation programme.
- **Work and education**
For those PwMS who are working or studying, communication difficulties, even if they are very subtle, can interfere with their activity.
- **Communication in advanced stages of the disease**
In advanced stages of the disease, communication problems can be more severe and affect the expression of basic needs and even of the need for help in an emergency. The expression of feelings and the maintenance of contact with relatives may also be limited by reduced communicative ability.

In summary, a reduction of social participation and emotional well-being occur in people with MS and communicative disturbances.

3 | Other aspects interfering with communication

Many PwMS have reported that their communication problems can come and go. If this is the case, these problems may not necessarily be revealed during testing. There are also some other factors that may affect speech and communication. It is important to look at the overall situation of the PwMS to bring out those problems.

- **Lack of self-awareness**

Cognitively impaired PwMS may additionally lack self-awareness of their cognitive disturbances, with a consequent significant reduction of their ability to acquire and use compensatory strategies.

- **Fatigue**

“I get tired from speaking, in the evening I hardly can speak.”

There is a difference between normal tiredness and fatigue associated with MS. Fatigue associated with MS is related to physical or mental effort, but the feeling of tiredness is stronger than would normally be expected. Fatigue can appear suddenly and also without any reason. In warmth, fatigue often gets worse. Nearly 80 % of persons with MS sometimes suffer from fatigue.

Fatigue makes it difficult to carry out the activities of daily life. Mental functions (cognition) may also be affected by fatigue. Every aspect of language requires cognitive processing and therefore cognitive fatigue may also have an effect on speech. For example, persons with MS have reported having more word finding difficulties when fatigued.

- **Physical restrictions**
Physical restrictions can also affect communication. For example a poor sitting position in a wheelchair weakens respiration. Disturbances of muscle function mean that body language doesn't always work properly.
- **Vision**
Vision problems are quite common in MS and this also has an impact on communication. If you don't see properly you miss a lot of non-verbal information from other people: gestures, expressions among others.
- **Medication**
The side-effects of some medicines commonly taken by PwMS can also contribute to worse communication. Anti-spastic medication such as benzodiazepines, baclofen and tizidine can produce weakness, fatigue and also cognitive impairment. Other medicines used for bladder control such as anticholinergic drugs can produce dry mouth and interfere with speech.
- **Lack of social environment**
"With whom should I speak? I see very few people around me, those around me speak even worse than I do, I spend most of the time at home on my own".
Reduced activity levels and reduced participation in social and work life may also have an impact on communication.
- **Behaviour and mood**
"I can't help speaking too fast; I don't feel like speaking".
Psychological aspects may also influence communication. A depressed person may feel tired and weak and this

can also be heard in the voice: it may be difficult to talk loudly enough. Anxiety can cause excessive muscle tension in the larynx (voice box) and make the voice sound strained. It may also be difficult to concentrate on precise articulation. As has been said emotional lability can also have a negative impact on communication.

- **Environmental noise**

In noisy places it is difficult to communicate. First, it is hard to concentrate on the conversation. Secondly, it may be exhausting to talk very loudly for a long time.

4 | Why and how often does this happen?

Speech and cognitive-communicative disorders are very common during the course of MS. MS is a disease of the white matter of the central nervous system (CNS), characterized by disseminated demyelination of neuronal axons within the CNS with relative preservation of axon integrity.

As it has been said one or several of the following factors can cause the communication problems experienced by these people:

- **Motor, sensitive and or cerebellar impairment.**

The damage to the central nervous system (CNS) caused by the demyelinated lesions can cause disturbances of muscular control over the speech mechanism, producing problems in oral communication due to paralysis, weakness or incoordination of the speech musculature.

- **Cognitive, behavioural and emotional disturbances.**

These disturbances are secondary to the brain damage affecting cortical and subcortical structures and the connections between subcortical structures and the cortex.

Speech pathology in MS

The reported prevalence of dysarthria in MS patients varies between 25 and 55%. The variation in the incidence depends on the severity, duration, and stage of disease progression.

Dysarthria can occur at various stages of the disease but in general speech disturbance is uncommon in the initial stage and tends to occur as a later manifestation. Initially the speech disorder is mild and the severity increases progressively with greater degree of neurological involvement; it is more pronounced in individuals in whom the disease process involves a greater number of neurological systems.

Since speech and swallowing share same anatomical structures and some physiological mechanisms speech disorders can be associated with swallowing disorders.

Cognitive communication disorders

Cognitive impairment (attention, memory, executive functions) can be one of the earliest features of the disease; its prevalence is estimated at 30 to 72%.

Behavioural disturbances, such as apathy or lack of inhibition and abnormal crying or laughing (emotional lability), as well as emotional disturbances (depression, anxiety) are also common in MS and can influence linguistic performance.

However, not all PwMS experience such difficulties: cognitive communication abilities are normal or nearly normal in approximately half of PwMS. Among those with disturbance of these abilities, some (the majority) experience mild to moderate difficulties, but there are also some PwMS who experience moderate to severe impairment of their cognitive communication abilities.

Other variables such as age, educational level, disease duration, visual impairment, physical disability and medication have not been demonstrated to have a direct effect on language performance of PwMS. However, it is possible that a combined effect of all

of these variables might contribute to the severity of language impairment. Regarding the MS course, it has been stated that people with chronically progressive MS might be more likely to experience cognitive communication difficulties than those with a relapsing-remitting course.

5 | Can I get help with my communication problem?

The PwMS with communicative problems or his/her family can ask for help. With appropriate intervention they can understand these problems and find and practice techniques and strategies to optimise communication.

When?

We recommend looking for help as soon as possible if changes in the communication activity of the PwMS are observed.

First of all, it is important to detect the problem early. Knowing what the problem is, where it comes from and how it can be handled decreases the degree of confusion, stress and even anger in both the MS sufferer and the people around him/her, including the medical and rehabilitation staff. It is important that they all work together to understand the difficulties. Otherwise, the people around the PwMS may have the feeling that the PwMS is teasing them or just seeking attention or they may ask things of the PwMS of which he/she is not capable. The PwMS may therefore have a feeling of not being understood, with consequent frustration and sadness, which generates a vicious circle in which the person loses motivation to communicate, speaks less and less and becomes increasingly isolated.

Secondly, being aware of the problem is the first step towards

doing something about it. Without awareness, little can be done. Awareness allows the PwMS and caregivers to find out tricks which help their communication and to be ready to understand and put in practice the strategies provided by the speech and language pathologist or any other professional who is helping them with this issue.

Moreover, incorporating changes in the way of doing things and in the environment requires good learning ability as well as flexibility and openness to change. Hence, it is advisable to introduce such changes when the person is cognitively fit and does not have many other strategies to pay attention to.

At any rate, intervention regarding communication is possible at any stage of the disturbance, from the very mild to the very severe stages.

By whom?

The PwMS needs to be treated as a whole. Variability of symptoms and of levels of impact of the disease makes the need for interdisciplinary intervention in MS obvious.

The health professional who usually leads and co-ordinates the intervention in communication is the speech and language pathologist (SLP). However, occupational therapists, neuropsychologists, psychologists, physiotherapists, social workers, doctors and nurses, among others, may play a role in the detection, assessment and treatment of communication disturbances in MS. The better the co-ordination between them, the better the possible results.

Where?

Any person with MS who experiences any degree or type of communication disturbance should use the health and social network around him or her to find help.

The neurologist, the general practitioner, or any other profes-

sional in the health team could be the first person to approach. One can approach the neurological unit of a hospital, a neurorehabilitation centre, an MS neurological unit, the “general health centre”, the MS clinic or day hospital or an MS association.

6 | How are communication disturbances detected and assessed?

At the first appointment the SLP interviews the patient and assesses communication with various tools. The function of speech muscles, tactile sensation, respiratory and phonatory function in speech and the quality of voice are examined. Cognitive communicative functions are also assessed. The needs and expectations of the affected person and of those around him/her are also collected and taken into account to establish the goals of the eventual treatment.

Interview

The SLP is first interested in background information about the person and about when, where and how the communication problems occur. The following questions about the communication problems may be asked:

- When did you notice that your communication had changed?
- Are there changes in your communication performance in the course of the day?
- Can you always make yourself clear by speaking?
- Does tiredness/fatigue affect your communication performance?

- Does talking/conversation make you tired?
- Are you still working / Are you retired?
- How much do you talk during a day? With whom?
- What would you like to improve in your communication?

Assessment of speech

PwMS may have problems with pronunciation and with the quality and maintenance of the voice, and their speech may therefore become slurred. First the SLP listens and evaluates the patient's speech during conversation. The patient is also asked to read aloud and the speech may be recorded. Velocity, stress, intonation and nasality of spontaneous speech are also analysed.

In addition, the SLP examines the motor, sensory and reflex functions of the cranial nerves. The examination includes muscle functions of the face, lips, tongue, jaw and soft palate.

All movements are evaluated for muscle tone, strength, range, speed, timing and accuracy. Intelligibility and prosody (velocity, stress and intonation) of speech are evaluated. Also the tactile sensation of speech muscles is evaluated.

The voice examination includes an evaluation of voice quality, loudness and pitch. The voice is evaluated in relation to the speaker and different situations.

The patient may be asked to read aloud and the SLP listens to his/her voice. Voice can sound rough, breathy, asthenic or strained, for example. In addition, the SLP examines respiratory muscle function and sufficiency of breathing of speech. It is also important to observe the breathing technique. Quite often patients with MS are unable to use their breathing capacity effectively.

Examination of cognitive communicative functions

Cognitive communicative disturbances may influence the efficiency and quality of communication. Therefore, it is important to assess cognitive performance, including language.

Both neuropsychologist and SLP may evaluate cognitive communicative performance. Naming, repetition, narrative discourse and word fluency tests give information about disorders of verbal expression. Other aspects that have to be assessed are complex auditory comprehension, different aspects of writing and reading and also the ability to use language pragmatically (this means, approximately, using the right words in the right place). More general cognitive functions which are necessary in communication are also assessed, such as attention, memory, executive functions and speed of information processing.

After the communication assessment has been completed the SLP discusses the test results with the patient and discusses how much the symptoms disturb the communication and activities of daily life. If speech therapy is needed, a therapy plan will be drawn up. If there is no need for intensive speech therapy, the SLP may give some tips and suggestions for home exercising.

7 | What is rehabilitation of communication? – Speech therapy

Rehabilitation is always directed at functional outcomes which have a positive impact on the quality of life of the PwMS and of the people around him/her.

The speech and language therapy programme often combines different procedures, all of them directed towards optimising the communicative skills. These procedures can be classified as follows:

- Awareness of the individual communication difficulties
- Minimisation of interfering factors
- Restitution
- Compensation
- Holistic intervention

Awareness of the individual communication difficulties

It is important that the affected person has as good an understanding as possible of how communication works and that he/she is aware of when communication breakdowns happen in his/her everyday life and of the causes of this breakdown. It is also important that the people around him/her and the professionals involved in his/her treatment are aware of this.

Minimisation of interfering factors

This intervention is directed at avoiding or reducing those factors which worsen communication (inappropriate posture, bad dentition, disturbances of mood and behaviour, secondary effects of drugs, etc.) and it is carried out in collaboration with the rest of the interdisciplinary team.

Restitution

The aim of this approach is to improve the impaired functions, maintain them or delay their deterioration. It can also be used to optimise functions which are relatively intact. It consists of systematic drill and practice of exercises. These exercises must be just one part of a broader intervention which assures transfer of the benefits into real life. The treatment programme has to be adapted to

the features and needs of each individual.

In the case of dysarthria, it consists of neuromuscular, neuro-sensory and psychomotor exercises, which are directed towards muscular strengthening, regulation of muscle tone and improvement of co-ordination and sensitivity. For instance, expiratory strength can be increased, with consequent improvement of the voice volume, and tongue movements can be improved in order to optimise articulation and swallowing. Exercises on articulation of words or sentences and conversation practice can also be included.

In the case of cognitive deficits, the intervention tries to optimise linguistic and cognitive functions involved in oral and written communication: attention, speed of information processing, cognitive flexibility, planning, word-finding abilities, complex verbal expression and comprehension, visual perception, etc. Part of this training can be done with computer exercises because the computer can offer motivation and autonomy advantages. Nevertheless, the therapist has to plan, supervise and complete the intervention to promote transfer into real life.

Functional skills training is needed, in the treatment of both dysarthria and of cognitive communication disorders, in order to facilitate the transference of acquired abilities into everyday life.

If possible, both speech and cognitive exercises should be practised regularly at home. In the case of fatigue, it is important to take this into account and to adjust the duration of the exercises accordingly.

Compensation

The aim of this approach is to improve communication with the help of various alternative strategies. In order to introduce these strategies, the affected person has to be aware of his/her difficulties and be able to learn the strategies. For instance, he/she can learn to pause frequently to breathe in when speaking, to pronounce each word separately if he/she can't be understood, to write down what he/she wants to say before making a phone call

or before going to the doctor or to make a list of characters who appear in a novel to facilitate reading.

Some people who have significant difficulties being understood can use a communication board with an alphabet or with a list of frequent messages in words or in pictures.

In the case of a faint voice but with adequate pronunciation, a voice amplifier can be useful.

There are some electronic and computer devices which can help to solve specific problems. For example, a person who has serious problems with communication can use a warning button to demand attention. Some patients who have difficulty remembering names can use a mobile phone to save and find names or pictures.

Computer or other devices with a synthetic voice used as augmentative and alternative communication systems (AAC) can be useful in some cases. However, many potential users may have difficulty using them because of motivational, sensory, visual or cognitive disturbances. Identification of the appropriate device and its implementation requires a specialised assessment.

Holistic intervention

The comprehensive/holistic approach adopts an integrated perspective and aims to improve communicative performance through a combination of interventions dealing with cognitive, emotional, motivational and interpersonal aspects.

It is important to provide guidelines to the relatives or close people and to encourage the affected person to engage in activities that interest him/her and thus promote communication at home, in associations, civic centres or in any other resources of the community.

People around the affected person (relatives, friends, professionals) have to know his/her cognitive and communicative abilities and difficulties and if any specific communicative strategies should be used.

It will be important for many people to facilitate access to the computer for different uses: writing, communication by e-mail, internet, cognitive exercises, and games. Even people with cognitive difficulties can benefit from the computer with the support of a third person.

8 | How to communicate efficiently

– Tips and tricks

General tips

- It is important that both you and the people around you are aware of your communication difficulties and of the skills you have to communicate. Inform them and let them know the tips and tricks which are useful for you.
- When you are having a conversation or reading, reduce noise and eliminate distracters (turn off the TV and radio, choose quiet places)
- Try to maintain a good posture. It will help you to speak better. Pillows and other supports might be useful to optimise posture. An occupational therapist or a physiotherapist can help you with this.
- Avoid doing two things at the same time. Concentrate on just one thing.
- Try to relax and take your time when speaking.
- Try to speak less if you are tired.
- It can be useful to previously plan some situations: make some notes before going to the doctor, going shopping, asking for information, etc.

- A notebook, a mobile telephone and a computer can help you to keep and find information to be used in conversations and giving messages.
- It may help you to get used to keeping routines. It will help you to manage your tasks, to remember information and thus also to express things more easily.
- Try to keep active and occupied with things that interest you. Maybe you can read, play games with people around you, converse about TV programmes, use the computer and internet. If possible, try to be in contact with other people. If you keep involved in interesting activities you will feel much more like communicating.
- The speech and language pathologist may help you to optimise your communication with regard to the motor, cognitive and functional aspects of communication.
- There are technical aids that can facilitate communication in some cases, such as a communication board (alphabet, words or pictures) or high tech aids such as a voice amplifier, a text phone, and so on. The speech and language pathologist can evaluate your case and give you advice.

During conversation

- Make sure your interlocutor is paying attention to you before starting to speak to him or her.
- You can explain your communication difficulties to the listener.
- Repeat things if necessary.
- Check to make sure that other people have understood what you said.
- Take a breath before speaking. Speak slowly and loudly.

- Introduce pauses: it may help you to keep your voice, to find words better, to remember what you want to say and to explain things better.

If you have significant difficulties communicating

- Put the emphasis on communicating, rather than accuracy of the sounds. Choose short and simple phrases if necessary.
- Introduce your topic with a single word or short phrase as a cue for the listener.
- Let him or her know whether or not you want the other person to complete your sentences for you.
- Use all resources available to convey the messages, such as pointing, gesturing or writing.

Tips for your family, carers and friends

- Have a good understanding of the communication difficulties and skills of the PwMS.
- Have a good understanding of other factors which interfere with communication in the individual, such as sensory, visual or motor impairments.
- Treat the person as an adult. Speak directly to the person with MS, not to the person who is with him/her. Use a normal tone of voice and body gestures.
- Don't centre the conversation with the PwMS just on the illness. Talk about other topics just as you normally do with other people.

- Pay attention to the speaker and watch him/her as he/she talks.
- In a conversation with a person in a wheelchair, try to sit down and communicate at eye level.
- Help the PwMS to be relaxed and try not to hurry the person.
- Find out whether the person with MS wants you to complete sentences for him/her.
- If you're not understanding what the person is saying:
 - Let the speaker know.
 - Repeat the part of the message that you understood.
 - Ask him or her to repeat what you didn't understand, rephrase it, write it or spell it out.
 - Ask him or her 'closed questions' to clarify things ("Do you mean... or?"; for example).
 - Use a checklist with possible topics to identify what he/she is talking about.
 - If you still don't understand him/her, make sure he/she is comfortable without any basic need and tell him/her that what he/she is attempting to communicate to you is important but that you are unable to understand at this particular time and that you will try to get the message at a later time.
- Conversation among several people is more difficult. Try not to suddenly and frequently change the topic and don't all talk together. Try to help the PwMS to take his/her turn to talk.
- If the PwMS has difficulty understanding and/or remembering complex information:
 - Provide written information and instructions
 - Instructions should be clear, consistent and step-by-step
 - Accompany verbal instructions with visual demonstrations.

Further reading

- www.mssociety.org.uk/about_ms/symptoms/speech_difficulties/tips.html
- www.asha.org/public/speech/disorders/dysarthria.htm
- www.mscafe.org
- www.msif.org.
- Murdoch B, Theodors D: Speech and Language Disorders in Multiple Sclerosis.
- Renom M, Sastre-Garriga J: Apoyo Neuropsicológico en la esclerosis múltiple. Timely New Topics in Medicine (www.ttmed.com/esclerosismultiple).
- Renom, M: Logopedia y enfermedades neurodegenerativas. Minusval, 149, pàg. 58-59, 2005

Rehabilitation in Multiple Sclerosis (RIMS),
the network of MS Centres in Europe
was created in 1991, in Milan, Italy to enhance collaboration
by the foremost MS Centres in Europe.
Today the Organisation has 40 member centres
throughout Europe.

The aim of RIMS is to link the European MS Centres in order to
encourage professionals interested in Multiple Sclerosis
to exchange their knowledge of clinical, scientific, social,
economical and educational matters about the disease and
to establish individual and scientific contacts between persons. In
addition, individual membership for those
who have a special interest in MS is welcomed.

RIMS has established a number of Special Interest Groups (SIG).
The groups aim to promote research and improve
the management of Persons with MS and their caregivers.

RIMS newsletter Network is published twice a year.

Find more information: www.rims.be

This booklet has been written by the members of
SIG on Communication and Swallowing