

## How to tell your family

Deciding whether or not to tell people that you have MS is a very personal decision. For many people with MS the disease is not clearly obvious, so there is a choice whether to disclose the diagnosis or not. If you need practical assistance, either daily or occasionally, this may dictate revealing that you have MS to those close to you. Your decision may depend on your relationships with others and how you think that they will react to the news. The following are general guidelines based on the experiences of many people with MS. If you have MS and are considering telling people about it, you should think of the following in the context of your own situation before making a decision.

### Speaking openly

The fact that a family member has been diagnosed with MS has inevitable consequences for the whole family. The degree to which a family is affected certainly depends on the degree of impairment caused by the disease. Nevertheless, the uncertainty resulting from the diagnosis of this disease affects the entire family. For the patient, aside from uncertainty about the course of the disease there is the added uncertainty of whether the family will be able to stand by and help cope with the illness.

The fear of becoming dependent on family members is shared by many people with MS and can lead to suppression of the disease symptoms and an overestimation of one's own strength. This leads inevitably to failures and despondency, and gives family members the feeling that their offers of help have been rejected. In turn this can result in withdrawal and a lack of readiness to help the family member with MS. A vicious circle begins. On the other hand there is also the danger of family members doing too much for them, even when they do not really need help and thus fall into an unnecessary dependency on the caregivers. Therefore, it is of utmost importance that the patient speaks openly with family members about the type and degree of help required. Together they must clarify how much help the family is able to provide and what sort of help the patient really needs and can accept.

One should always consider that aside from family members, other people can be called upon to help, in order to avoid overtaxing family capacities. It is important that the MS patient and the other family members both live and control their own lives as much as possible, including leisure time and hobbies.

A balance between rest and effort is important; sufficient sleep is a must and fatigue should be avoided. For the family this might mean, for example, that joint activities are rescheduled to morning hours, long evenings are avoided, brief rest pauses are planned into any shared undertaking and common work is distributed in such a way that the MS patient is not overtaxed.

### Professional help

If professional help is necessary, family counseling or family therapy may be available (in which the whole family consults a therapist together). Consult your doctor on how to obtain this help. In certain circumstances individual consultation or therapy for your partner might be advisable. Group courses for relatives and caregivers are also offered. Frequently, it is very important to relieve the close relatives of their duties; they often feel burdened by a high level of guilt and rarely allow themselves any time for themselves (for instance to take a holiday alone or pursue a hobby).

It is important both for the family and the person with MS to learn that the one with MS has several roles within the context and course of the disease. The MS patient can be anything from externally fully healthy and not at all handicapped to acutely affected or even chronically affected with more or less severe loss of abilities in a great variety of ways and at different times.

All of this assumes that open discussions about the disease were able to be held beforehand. This is not always possible when there are very small children in the family, of course. Nevertheless children have a fine sense of when something is no longer alright, and they might feel embarrassed about it and do not understand why the father or mother can no longer play with them the way they used to do. For instance, they see perfectly well that the father/mother can no longer walk properly. Children quickly become anxious and fear that the parent might die, that all of a sudden they will be left all alone. Occasionally the children even feel responsible for the disease, guilty that this has happened. For this reason it is absolutely necessary to speak openly with the children about the illness. How detailed the information is depends on their age and maturity.

Certainly there is the danger that a disease such as MS involves so many difficulties for the family that it tears it apart. On the other hand family members who have a loving and intimate relationship also have the opportunity of bearing the common burden of MS, and thus grow even closer and more intensely committed.

## **Telling young children**

It is probably not useful to make a formal announcement about MS to very young children, but it is important that their questions are answered as and when they occur. Instinctively children are aware that something is wrong and that you are worried. You need to be aware of this and understand that their behaviour can sometimes be disturbed. The truth is hardly ever as frightening as their fears. A number of the national MS societies have booklets for children available that you may find helpful.

## **Telling older children**

Older children and adolescents need to be informed but may require a more careful approach. Although they can appear outwardly calm and possibly even indifferent, they are most likely very concerned. Their anxiety can be helped by information. Their concerns need to be addressed as they arise and they need to know that you are willing to speak with them as issues come up. The opportunity to read selected literature from the national MS society may be helpful.

Adolescents feel that they should be treated as adults and if they are not allowed to play a responsible part in a family problem they can feel both hurt and resentful. As a result they may start behaving in a destructive way. If, however, their cooperation is encouraged they can become surprisingly mature and a source of strength. Trying to keep your problem to yourself will not spare them any anxiety.

## **Telling parents**

Telling parents of your diagnosis can also be difficult. It is very hard for parents to accept their child's diagnosis and it is extremely important to be sensitive to their feelings and needs. Mothers, especially, will probably be extremely protective and many parents will feel that they are to blame.