



**National
Multiple Sclerosis
Society**

733 Third Avenue
New York, NY 10017-3288

Clinical Bulletin

Information for Health Professionals

Improving Adherence to Therapy with Immunomodulating Agents

by Nancy Holland, EdD

Emerging research in multiple sclerosis suggests that even early in the disease course, changes are occurring that may have permanent neurological consequences. The argument is building, therefore, to intervene early with one of the approved disease modifying therapies that have been shown to reduce relapse activity in persons with relapsing forms of MS, to reduce brain lesion activity on magnetic resonance imaging, and possible to modify disease progression.

The therapeutic benefit of the immunomodulating agents, however, cannot be attained unless patients continue to use them. Of the six therapies approved to date by the U.S. Food and Drug Administration, four are administered by injection (Betaseron[®], Avonex[®], Copaxone[®], and Rebif[®]). Problems with adherence to pharmacologic and nonpharmacologic treatments are well-documented for many disease states, and it is believed that adherence may be especially problematic among people with MS, particularly in regard to accepting or initiating an injectable medication or discontinuing its use after a brief treatment duration.

Health care professionals can influence patients positively or negatively. In light of extensive data that support the benefits of early intervention, it is recommended that the medical team make a commitment to promoting acceptance and maintenance of immunomodulating therapy. This is done most effectively when the health care providers understand the factors affecting adherence and are sensitive to the patient's "stage of readiness" for treatment. The following discussion pertains to those patients whose physicians have prescribed one of the four injectable medications; the adherence issues relating to the other two treatment options (Novantrone[®] and Tysabri[®]), which are delivered by infusion, are likely quite different.

FACTORS AFFECTING ADHERENCE TO TREATMENT

A host of factors affect MS patients' adherence to treatment. There are patient-related factors, treatment-related factors, and disease-specific factors. These factors vary from person to person, but principal among them are:

- ◆ "Invisibility" and unpredictability of the disease
- ◆ Inadequate motivation and coping skills
- ◆ Lack of knowledge
- ◆ Fear of needles
- ◆ Feelings of hopelessness and resignation
- ◆ Occurrence or fear of side effects
- ◆ Physical impairments
- ◆ Cognitive impairment
- ◆ Previous negative experiences with health care providers
- ◆ Inconsistent messages from health care providers

A full understanding of the individual's knowledge about multiple sclerosis, personal belief system, lifestyle, and support network is the first step toward helping a patient accept and adhere to ongoing treatment. Specifically, the health care team should try to determine the patient's:

- ◆ Understanding of the treatment benefits and risks
- ◆ Perception of his or her illness
- ◆ General mood and level of self-esteem
- ◆ Lifestyle and daily living situation
- ◆ Level of support from family and the community

A MODEL FOR ADHERENCE

Patients' attitudes and beliefs are dynamic, and environmentally and culturally based, as are their medical and personal situations. Therefore, their tendency to accept or reject therapy may change over time. Health care providers can intervene at any point to influence adherence. Interventions will be more effective if they match the patient's readiness for change.

The application of the transtheoretical model of behavior change is useful in the development of strategies to encourage the initial and sustained use of disease-modifying agents (Holland et al., 2001; Cassidy, 1999; Prochaska and DiClemente, 1992). This model, which has been used in other chronic illnesses, describes the process of change as long-term and dynamic, incorporates individual variables, and acknowledges that patients move through stages of change, not necessarily in a linear fashion.

These stages and the appropriate interventions, as they apply to MS, are as follows:

- ◆ **Pre-contemplative stage:** Patients with newly diagnosed MS are not yet contemplating treatment; in fact, they may be in a state of denial over their illness and may reason that they are not yet “sick enough” for therapy.

Intervention:

Explore the patients’ understanding of MS, personal beliefs about therapy, and perceived obstacles to starting therapy. The aim is to foster increased awareness of their disease and a better understanding of their personal barriers to treatment.

- ◆ **Contemplative stage:** Patients are actively considering therapy but with some ambivalence, and are becoming more open to educational efforts.

Intervention:

Educate with a focus on the anticipated benefits of treatment, the risks associated with no treatment, and a clarification of the patients’ goals. Following this intervention, patients should be able to describe the treatment choices and processes.

- ◆ **Preparation stage:** Patients express the determination to start treatment within the next month. Patient, physician, and nurse make a decision as to the most appropriate of the few available drugs.

Intervention:

Work with the patient to develop an acceptable treatment plan: address the details of the treatment regimen; establish a convenient injection schedule; involve the health care team and, if applicable, the pharmaceutical assistance program or insurance plan; and involve family or friends.

- ◆ **Action stage:** Patient is engaging in therapy with a disease-modifying agent, initially supervised by his or her physician and nurse.

Intervention:

Be available to address concerns, problem-solve, and provide continuing support. Frequent phone contact is important.

- ◆ **Maintenance stage:** Patients strive to adhere to their commitment to treatment. They will continue on treatment unless serious side effects appear, severe relapses occur, the disease progresses rapidly, more effective therapy becomes available, or disease remission leads them to believe treatment is no longer needed.

Intervention:

Provide continued support and periodic follow-up. When patients go off therapy, re-assess the patient’s stage of readiness and take steps appropriate to that stage.

REALISTIC EXPECTATIONS

In discussing multiple sclerosis with patients, health care providers face the following challenge: to support the patient’s need to hope for a benign disease course while emphasizing the potential benefit of early treatment for a disease that is unpredictable and largely invisible. The value of a

trusting and consistent relationship between the patient and the health care team cannot be overstated.

It is essential to share information realistically with compassion and with hope. It is the mission of the nurse and other team members to help patients reframe their options within a framework of support, education, and advocacy; a strong therapeutic partnership is key.

REFERENCES

- Cassidy CA. Using the transtheoretical model to facilitate behavior change in patients with chronic illness. *J Am Acad Nurse Practitioners* 1999; 11(7):1281–1287.
- Holland N, Wiesel P, Cavallo P, et al. Adherence to disease-modifying therapy in multiple sclerosis: Part I. *Rehabilitation Nursing* 2001; 26(5):172–176.
- Holland N, Wiesel P, Cavallo P, et al. Adherence to disease-modifying therapy in multiple sclerosis: Part II. *Rehabilitation Nursing* 2001; 26(6):221–226.
- Prochaska JO, DiClemente CC. Stages of change in the modification of problem behaviors. In Hersen M, et al. (eds): *Progress in Behavior Modification*. Sycamore, IL: Sycamore Publishing Co., 1992.

Concepts for this Clinical Bulletin were developed by the following panel convened to address the issue of adherence to immunomodulating therapy by people with MS.

Nancy Holland, RN, EdD, Chair	Rosalind Kalb, PhD
Phyllis Wiesel, RN, BSN, Co-chair	Linda Morgante, RN, MSN, CRRN
Pamela Cavallo, MSW, CSW	Marie Namey, RN, MSN
Clayton Edwards, RPh, MAB, PAHM	Margie O’Leary, RN, MSN
June Halper, MSN, ANP, FAAN	Lori Smith-Williamson, RN, MSN, C-ANP

Avonex is a registered trademark of Biogen Idec

Betaseron is a registered trademark of Bayer Schering Pharma Aktiengesellschaft

Copaxone is a registered trademark of Teva Pharmaceutical Industries Ltd.

Novantrone is a registered trademark of Immunex Corp

Rebif is a registered trademark of Ares Trading S.A.

TOUCH is a trademark of Biogen Idec and Elan

Tysabri is a registered trademark of Elan Pharmaceuticals, Inc.

Special thanks to Caroline Helwick for her contribution to this publication.