



## **Wellness for People with MS: What do we know about Diet, Exercise and Mood And what do we still need to learn?**

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### **Introduction**

Wellness – and the strategies needed to achieve it – is a high priority for people living with multiple sclerosis (MS). People want to know what they can do today to feel their best, and whether lifestyle interventions can impact the course of the disease.

In the pursuit of personal wellness, people with MS have felt frustrated by a lack of support from healthcare professionals, who say there is not sufficient scientific evidence to provide guidance in this area, or who may not have the time, expertise or interest to discuss it with their patients. As people develop their MS management strategies, they want to understand the role of mainstream medicine, including disease-modifying therapies and symptom management medications, as well as the role of wellness behaviors such as diet and exercise. Are both of these approaches necessary? Can or should wellness strategies be used instead of medication(s)? How can the greatest benefits be gained, and how soon?

Three areas of wellness consistently rise to the top for people with MS. They want to know how they can manage their MS with **diet** and with **exercise**. People with MS also identify as a priority learning how to manage the mood changes – particularly **depression** – that are so common with this disease, in order to achieve and/or maintain emotional wellness.

To address these priorities, the National MS Society convened a group of people with MS, healthcare professionals, researchers and Society staff in November 2014 to take the following steps:

- Review the current knowledge in the areas of **diet, exercise** and **emotional wellness**
- Identify gaps in knowledge in these areas in order to inform the Society's research agenda
- Suggest educational resources and support programs in these areas to better meet the needs and interests of people living with MS

This paper reflects the experiences, opinions and consensus recommendations of the individuals who participated in this meeting.

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## Achieving Wellness

Wellness is a lifelong journey through which people develop an awareness of, and make positive choices about, their behaviors, lifestyle and activities that enable them to lead their best lives.

Wellness is personal, multidimensional and holistic. Wellness involves **physical, emotional, social, intellectual, occupational** and **spiritual** dimensions, with each existing along a continuum. Achieving wellness does not occur quickly or with a single behavior. Rather, it is a lifelong journey that involves taking action and making lifestyle choices with the goal of attaining optimal well-being. The journey towards optimal well-being is unique for each individual – and attainable for everyone within the context of his or her priorities and abilities.

## Wellness:

### What Do We Know? What Questions Remain to be Answered?

A recent online search for information about diet, exercise and mood in MS yielded a total of close to 50 million hits. The challenge is in trying to make sense out of this complex array of facts, opinions, advertisements and personal experiences. Even within the scientific literature, the available information is inconclusive and sometimes contradictory.

When reviewing scientific studies, it is important to consider the quality of the evidence they provide. Many systems for classifying scientific evidence are available, but all agree that randomized, controlled trials (such as those used to evaluate a new medication) offer the most reliable information, while the least reliable information comes from studies with no control group, reports of individual cases, anecdotes and opinions. However, even when studies have an adequate structure and design, they may not include enough participants to offer conclusive evidence about the impact of a treatment or intervention. With these issues in mind, the experts in each focus area summarized the available data and identified key questions that remain to be answered.

## Diet

The following studies suggest that diet may play an important role in determining the risk of MS and of disease progression:

- Research findings point to obesity<sup>1</sup> as a possible risk factor for developing MS. The incidence of MS appears to be increasing worldwide at the same time that caloric intake and being overweight or obese are increasing. In recent studies, obesity and body size at age 18-20 were associated with an increased risk of MS, as was higher Body Mass Index (BMI) at age 7-13.
- Recent evidence points to sodium intake as a potential factor in MS disease activity. Sodium is a primary component of salt. In an observational study, people who consumed a moderate or high amount of sodium had a higher rate of relapses and a greater risk of developing a new lesion on MRI than people who consumed a low amount of sodium.
- Several studies have suggested a role for low levels of vitamin D in disease onset and disease progression. Vitamin D supplementation is currently being evaluated in a randomized, controlled clinical trial in order to determine whether this apparent relationship is real or coincidental, and whether the potential benefits outweigh any risks for people with MS.

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<sup>1</sup> As defined by the World Health Organization, obesity is defined as a Body Mass Index (BMI) – weight in kilograms divided by the square of height in meters – kg/m<sup>2</sup> equal to or greater than 30.

- The potential role of polyunsaturated fatty acids (PUFAs) in slowing disease activity has also been studied, with mixed results. As is being done with vitamin D supplementation, carefully controlled trials are necessary to identify potential benefits and risks.

Overall, research studies in the area of diet have generally been of inadequate size and design to provide useful information about dietary strategies in MS. The evidence available thus far related to dietary factors is insufficient to establish either **efficacy** (how well a particular diet or supplement works in the structured environment of a controlled clinical trial) or **effectiveness** (how consistently or persistently people can use a diet or supplement in everyday life).

The following questions need to be answered about diet in MS:

1. What is the impact of a given dietary strategy on the underlying disease process in MS? On symptoms?
2. Are different dietary strategies effective for different individuals, or does one type of diet fit all people with MS?
3. Is it possible for people to change their eating habits over the long-term?
4. How can researchers identify those dietary interventions that might hold promise for people with MS?
5. Do dietary interventions change the way MS medications are absorbed and used by the body?

## Exercise

A substantial body of research demonstrates that exercise is good for a person's overall health and for reducing other health conditions (co-morbidities). Obesity, for example, may increase a person's risk of developing MS and may contribute to a poorer outcome (prognosis). The research in MS has also demonstrated that exercise training is effective for improving aerobic capacity and muscle strength, mobility, quality of life, and symptoms of fatigue and depression. However, the efficacy or effectiveness of any specific exercise program for people with MS has not been established.

Of note, the amount of sedentary behavior among people with MS is alarmingly high, regardless of their physical abilities or limitations; yet we know very little about strategies that help people become more physically active.

The following questions need to be answered about exercise in MS:

1. Is exercise training a disease-modifying and/or symptomatic therapy? Does exercise influence the underlying disease process in MS?

2. What is the effect of exercise on symptoms, including cognition, sleep and pain? Does exercise help manage more severe symptoms as well as milder symptoms?
3. What is the optimal amount (intensity and frequency) of exercise for people with MS? Does the optimal amount vary by severity of the disease?
4. How do we encourage and support the initiation and maintenance of exercise behaviors in people with MS? What is the role of healthcare professionals in encouraging people with MS to exercise?
5. What are the causes of sedentary behavior among people with MS? Can increasing a person's overall activity level produce benefits similar to those seen with a regular exercise program?
6. How do individuals with MS differ (in terms of disease course, disease severity, symptoms) in the kinds of exercise that would be most beneficial?

### Emotional Wellness

From the time of diagnosis, people with MS use a variety of self-management strategies to maintain or enhance their emotional well-being in the face of MS-related challenges. However, due to a variety of factors (small study sizes; inadequate design of clinical trials; and a lack of consistency in the groups studied and in the way anxiety, depression or stress are defined and measured), the research has not determined the efficacy or effectiveness of most of these interventions. Thus far, the research suggests that:

- **Exercise** – (aerobic and, perhaps, resistance training) may help reduce depressive symptoms and being physically active may help people feel less depressed over time
- **Telephone-delivered physical activity counseling** (including motivational strategies, goal-setting, action planning) – may reduce the severity of depression in people who become more active
- **Acupuncture, Feldenkrais, guided imagery, hypnotherapy, massage, meditation, mindfulness, music therapy, prayer and spirituality, Tai chi, yoga** – may be effective in reducing mild to moderate depressive symptoms, anxiety and stress
- **St. John's wort** – is probably effective for treating mild to moderate depression
- **Adaptive coping and solution-focused coping** – help to reduce anxiety
- **Stress management strategies of various types** – may help to reduce stress

People with MS who experience more severe mood disturbances, including major depression, may be unable to engage actively or effectively in any wellness strategies, including emotional wellness strategies, physical exercise or healthy eating practices. For these individuals, identifying and treating the mood disturbances is necessary before they can embrace lifestyle changes that may lead to wellness.

The following questions need to be answered about emotional well-being in people with MS:

1. Can we demonstrate in controlled clinical trials the impact of wellness behaviors such as guided imagery, prayer and spirituality, and massage on feelings of depression, anxiety and stress?
2. Can we identify a “menu” of effective strategies (including medication, psychotherapy and wellness behaviors) that could be tailored to the emotional needs of each individual at different points in time?
3. How do we attract, train and retain mental health professionals in MS care?
4. How can we ensure that people at risk for significant mood disturbances are identified at different points in the disease course?
5. Who, in addition to mental health professionals, can safely and effectively treat mild to moderate mood issues?

## Wellness Research:

### Challenges to Addressing Gaps in our Knowledge

The review of the published research about diet, exercise and emotional wellness highlighted the importance of determining the relative **efficacy** and **effectiveness** (see p. 4) of wellness strategies – alone or in combination – for managing symptoms, reducing other (co-morbid) health conditions and enhancing the impact of disease-modifying therapies on MS disease activity.

Several challenges must be overcome to address these gaps in knowledge and establish a successful research agenda:

- How to identify and prioritize the target groups to study, for example:
  - Individuals with relapsing disease or those with progressive disease
  - Individuals who are newly diagnosed, for studies designed to prevent symptoms or progression, or those with more progressed MS for studies designed to intervene and provide disease modification or symptom relief
- How to determine the appropriate control group for each study in order to demonstrate most clearly the impact of the intervention being studied, for example:
  - A group on the waiting list for the intervention
  - A group receiving a sham intervention (placebo) or a different treatment intervention (known as an “active control”)
  - A group receiving standard care

- How to address the challenges in adhering to a wellness intervention (for example, a diet, exercise regimen, or mindfulness protocol) over long periods of time
- How to address the ways in which significant mood changes and/or MS-related cognitive changes may impact a person's ability to engage in wellness activities like exercise and eating a healthy diet
- How to find and train knowledgeable scientific reviewers to assess wellness research proposals that are somewhat different from proposals submitted for basic science (laboratory) research
- How to address concerns some in the medical community may have that wellness research is not a high priority
- How to expand resources to fund large-scale, well-designed and controlled multi-site studies in wellness

## **Wellness Research Recommendations**

After careful consideration of the identified research gaps and challenges, the following recommendations were made:

1. Engage research design experts to address the challenges identified within and across wellness areas
2. Stimulate collaborative research efforts, similar to what has been done in the areas of genetics, nervous system repair and progressive MS, to ensure that the best minds are working with speed and effectiveness in wellness research
3. Identify funding partners who share our interest in increasing knowledge about wellness interventions in MS

## **What Can We Do Now?**

In each of the targeted wellness areas – diet, exercise and emotional health – strategies were identified to expand education and resources for people with MS and healthcare providers to promote physical and emotional well-being.

### **Diet**

- Provide clear recommendations to people with MS based on what is known today about the role of diet in overall health:
  - Limit sugar and processed foods (particularly those high in sugar, salt and sodium)

- Increase fruits and vegetables
- Choose lean sources of protein
- Choose healthy fats
- Consume adequate fiber and fluids
- Provide unbiased information about popular “MS diets” in order to support educated decision-making
- Focus on reducing obesity since it appears to increase the risk of MS, and also increases the risk for other health conditions that can worsen a person’s MS
- Consider creating dietary guidelines for people with MS

### Exercise

- Provide clear recommendations based on what we know today about the impact of exercise on overall health, MS symptoms (including mobility, weakness, balance, cognition, mood, pain) and quality of life
- Educate healthcare professionals about the role of exercise in health and MS management, and encourage them to talk to their patients about “exercise as medicine”
- Partner with community organizations (for example, the YMCA) to provide exercise programs for people with MS
- Consider adopting and distributing the Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis

### Emotional Wellness

- Develop strategies and tools to increase doctor-patient conversations about emotional wellness beginning at the time of diagnosis, such as:
  - Toolkit for people with MS to identify mood changes in themselves and talk about those changes with their healthcare provider(s)
  - Information and tools for healthcare professionals to talk about mood changes with their patients and to facilitate referrals to the Society and mental health professionals in the community
- Identify proactive strategies to promote emotional well-being and prevent significant mood disruption in people newly-diagnosed with MS
- Increase the numbers of individuals (peers with MS, Society MS Navigators, mental health professionals) who can deliver effective interventions (prevention, diagnosis, treatment, support) from the time of diagnosis onward



## The National MS Society's Response: Next Steps

Based on the recommendations from this meeting, the Society will:

- Convene a work group to address the following concerns about depression in MS (planned for June 2015):
  - Lack of well-designed studies to identify the cause(s) of mood changes and the interventions that might be helpful for each individual
  - High prevalence of severe depression and anxiety among people living with MS
  - Under diagnosis and under treatment of depression and other mood changes in people with MS
  - Complex, probably inter-related causes (immune changes and changes in the brain, as well as psychosocial stressors) of depression in MS
  - Impact of depression on quality of life, ability to take care of oneself, adherence to treatment, and MS symptoms such as cognition, pain, fatigue
  - Possible role of depression and stress in central nervous system inflammation and the disease process
  - Insufficient numbers of mental health professionals to provide diagnosis and treatment
- Design a strategy to educate healthcare professionals about the role of wellness in MS comprehensive care, and the importance of diet, exercise and emotional well-being
- Create an MS Wellness Research Network – including researchers in the areas of diet, exercise and mood, as well as researchers from other disease groups and experts in study design and statistical analysis – with the goal of developing study design criteria and specific research methodologies for wellness-focused research
- Educate scientific reviewers about how to evaluate wellness research proposals
- Develop a long-term strategy for funding research in wellness interventions
- Evaluate existing programs and explore development of new programs that would inform, encourage and facilitate participants' pursuit of personal wellness
- Develop a “white paper” for publication in a peer-reviewed journal, which summarizes current knowledge and knowledge gaps concerning the role of wellness strategies in MS management, as well as research and programmatic recommendations

## Summary

People living with MS identify wellness as a high priority in their lives. They want to know what they can do today – particularly related to diet, exercise and emotional wellness – to feel and function at their best. In addition, they want the support of knowledgeable healthcare professionals who are armed with accurate information about wellness interventions, as they pursue their wellness goals. At a recent meeting convened by the National MS Society, people with MS, healthcare professionals, researchers and Society staff summarized what is currently known about diet, exercise and emotional issues in MS; identified key questions to be answered in each of these areas, along with the research gaps and challenges to be addressed in order to arrive at the answers; made specific programmatic recommendations to ensure that people living with MS are getting the personalized support and information they need to achieve wellness; and outlined next steps to move this important priority forward.