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[INTRODUCTION >](#)

Every year, 10,000+ people are diagnosed with MS. It most often strikes young adults—women and men between the ages of 20 to 40 years old—who are in the prime of their lives, building their families and careers. The lack of patient-focused, Internet-based information has far-reaching—even life-altering—effects on their lives.

When patients are diagnosed, a majority of them turn to the Internet to learn about MS. A Yahoo! search on Multiple Sclerosis produces 14.2 million hits and is rife with misinformation. How does someone make sense of it all? How do patients separate fact from fiction

TurnFirst.org gives the newly diagnosed and their families a trusted place to turn when they get the news.

TurnFirst.org is a collaboration between patients and medical professionals to provide support to people newly diagnosed with Multiple Sclerosis and their families. By giving them accurate, Internet-based information and resources, TurnFirst will help patients be better prepared to take on both the physical and emotional challenges of MS, advocate for themselves, and set a course to lead fulfilling and productive lives. TurnFirst will give hope and encouragement by alleviating the fear, confusion, and isolation that often accompany the early stages of MS. It will be a unique resource for patients, their families, and their medical team to understand MS, explore their treatment options, connect with others, and find additional resources.

[THE INTERNET EFFECT >](#)

Americans are seeking health information online. 8 in 10 Internet users look for health information online (95 million American adults).

More Americans go online for medical advice daily than actually visit health professionals. 6 million Americans go online for medical advice on a typical day.

A specific disease or medical condition is the #1 health-related topic researched online. That accounts for 66% of all U.S. Internet users and 93% of those who have used the Internet for health research.

The information patients find affects their care and treatment decisions. 68% of online health information seekers report it had “some impact” on their decisions related to their own health care or a loved one’s care; 16% said it had a “major impact.”



■ > Some Impact
■ > Major Impact
■ > No Impact

Americans are less likely to seek or use information from pharmaceutical web sites because of the obvious marketing push. Only 32% of 18-29 year-old Internet users have gone online to find information about prescription or over-the-counter drugs. 47% of health seekers have decided not to use information they found because the web site was “too commercial and seemed more concerned with selling products than providing accurate information.”



■ > Internet Users Searching Drug Info
■ > Not Searching Drug Info

This suggests that patients place a higher value on independently validated treatment information than on information direct from a drug company. It also suggests that patients are more likely to find this information if it is on a web site related to a specific disease or medical condition, not a specific treatment.

[WHY GOOD ONLINE INFORMATION MATTERS >](#)

Misinformation online has far-reaching—even life—altering effects on patients. Misinformation leads to:

- **A lack of or improper treatment.** Confused patients often fail to pursue pro-active treatments that can alter the course of the disease. Furthermore, patients may be advised to do things (such as to stop exercising) contrary to their best interests. According to a just-released U.S. study, 62% of MS patients seeing a neurologist and 92% of MS patients seeing a general internist are not taking immunomodulatory agents.
- **Dangerous alternative treatments.** The lack of clear treatment options causes some patients to turn to experimental or “holistic” treatments that are potentially harmful. These can include vitamin and supplement therapies that have unintended negative effects on the immune system.
- **Misguided life decisions.** An MS diagnosis may cause patients to give up unnecessarily on dreams and ambitions that bring meaning to their lives. For example, a young woman may be discouraged from having children—despite studies that suggest that pregnancy does not worsen or alter the course of MS.
- **Loss of hope.** The most dangerous effect of all is the loss of hope. Just because we don’t have a cure yet doesn’t mean patients don’t have good tools to fight this battle and thousands of reasons to believe that the battle is one they can win. Our best weapon is a positive attitude and accurate information to guide our decisions.

[THE TURNFIRST APPROACH >](#)

TurnFirst.org is an innovative way to support a new generation of patients who increasingly turn to the Internet for medical information. **TurnFirst.org will offer a step-by-step approach** to helping new patients educate themselves and connect with MS experts and other MS patients using:

- **MS 101**—We are creating a guided, easy-to-follow “curriculum” for learning about MS.
- **MS Mentor**—A virtual “mentor” will guide patients through the curriculum. It’s like having a friend who knows MS talk patients through their next steps in coping with their diagnosis, planning a strategy for sharing their news and working with their medical team to understand their options.
- **Forums**—There will be a place for patients to connect with others going through this experience.
- **Resources**—The site will provide a comprehensive listing of articles, tools, organizations, and other resources that will give patients an essential understanding of the support available in the MS community.
- **Personal Page**—Registered patients will be able to save and organize their information in a private page on the site and access it any time. It will give them a tool for tracking, sharing, and managing information.

Why is TurnFirst.org Unique?

- Focus on the needs of the newly diagnosed and their families
- Educational program, not just a “library” of pamphlets and links
- Depth of information
- Patient- and doctor-driven
- Innovative use of technology
- Non-commercial

[REFERENCES >](#)

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