



**Too Tired to Cook, Too Tired to Chew...
From Inception to World Wide Distribution
The Evolution of a Low Cost Web-Based Patient Education Piece
By Susan Goodman, MA, RD, CDE, CDN**

Two years ago I was approached by Shirley Brown, Website Project Director for the Consortium of Multiple Sclerosis Centers (CMSC) to develop an evidence-based article on nutrition and fatigue in multiple sclerosis; the article was to be peer-reviewed and posted on the CMSC Website, www.mscares.org. An exhaustive search of the literature revealed no controlled studies of fatigue in MS that involved nutrition. Medication, time and energy management, deconditioning, swallowing, respiration, depression, were being investigated in relation to fatigue and fatigability. There was very little in the literature about food, nutrition, diet and MS at all. There also seemed to be very few patient education pieces available on the topic. I, therefore, decided to develop a list of talking points for doctors and nurses to share with their patients to help them eat well when they had limited energy.

The content would be simple and direct; the attitude positive and upbeat; the suggestions achievable and empowering. Ten talking points were developed and embellished. Basic nutrition concepts were included; as the CMSC website reaches an international audience, recommendations for good nutrition from around the world, based on local healthy guidelines, using native foods and food patterns were included. Convenience in all of its forms – from partially prepared food items to home delivered meals would be emphasized. Menus would be included for low cost, simple to prepare and easy to chew meals and snacks. Four days worth of menus would be developed. Seasonal ingredients could be emphasized for variety.

The final draft was completed and posted on the Website. Feedback was positive. A short time after the posting, I was contacted by a speech-language pathologist from Pennsylvania. She had read the article and thought the suggestions would be helpful for both her patients and their caregivers alike. She stated that she did not have a handout on this topic but that she also had a limited budget for educational materials. She therefore asked if we could make copies for her Center.

A protocol was developed for use by any Center requesting to make copies for distribution. Upon receipt of a written request from the director of the center, permission would be given to allow the Center to reproduce the information to distribute to patients and credit was to be given to the Consortium and to the author. It seemed simple enough to download the article directly from the internet and to distribute it. However, it soon became apparent that it was not possible to download the information directly from the Website because the online format did not fit properly on a page. Also the copy was not visually appealing; when the menus were printed out they were not properly formatted and were difficult to

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understand. To develop a more readable product the content would have to be retyped and reformatted by each Center before being placed on its letterhead. To assure accuracy, the author would need to approve the final copy before it could be printed and distributed.

It soon became apparent that editing would become very cumbersome and time consuming. Each version would have to be checked and rechecked for accuracy of copy, involving many revisions back and forth. There was too much room for errors in spelling, grammar, punctuation. There could be misinterpretation of content and selection of less than optimal format, font and/or type size. There would be no uniformity.

It was, therefore, decided that a more uniform product could be obtained by creating a version in Adobe PDF® format at website central. This was a collaborative effort by the Website Manager and the author. The author would be able to control the format of the content of the product as well as the spelling, capitalization, punctuation, font and type size. Copies would be standardized for all users. The original would be copyrighted by the Consortium. The downloadable version would be on CMSC letterhead, showing the copyright, the author and the date of the publication. Content could easily be updated and the original revised as needed. Single or multiple copies could be downloaded from the internet as needed for distribution to patients. There would be no need for inventory or storage by the consortium or the member centers. Acquisition costs would be minimal.

The standardized Adobe PDF® version is now available on the CMSC Website. It can be downloaded by any visitor to the site; any Center can use it for patient and/or caregiver education. This process has proven to be an easy, cost effective way to develop a copyrighted educational tool. To date, the piece is being used from Pittsburgh to Australia to Canada.

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