

Advice for the Newly Diagnosed

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In my last column, I discussed the value of knowing the “bald facts” on the risks of disabilities and premature death faced by persons with MS. Notably, it has only been relatively recently that doctors have been telling their newly diagnosed patients about such risks and this trend began when drugs first became available for treating MS. Basically, doctors now use the “bald facts” as a means of convincing their patients to use one of the drugs. And they don’t spend much time doing this. A recent study found the initial consultation with the neurologist was less than 15 minutes in the majority of cases. Of course, in such a rushed meeting, the doctors tell their patients ONLY about the drugs and nothing about any other treatment which has the potential to slow or halt the MS disease process and hence stave off any long term disability.

When it comes to the current MS drugs, it is important to keep in mind that very large trials with over 1000 participants were needed to demonstrate a very small benefit for each of the approved drugs and none have demonstrated any direct effect on slowing the accumulation of disability. The bottom line with such results is that an MS drug may or may not have a positive effect for a given individual. Exactly the same thing may be said of other treatments which are supported by scientific data and by abundant anecdotal reports. So why don’t the doctors tell their newly diagnosed patients about all treatments which have a reasonable chance of being beneficial, especially those which are low cost and perfectly safe?

To find an answer to this question, it is important to realize that most neurologists are “on the take”. This means that they accept money and gifts from drug companies, and once a neurologist does that, they are compromised in terms of any decision involving drugs and alternatives to drugs. Let’s face it, if a drug company gives the neurologist and their family an all-expense trip to Paris (a relatively common practice), it is hard to believe that the neurologist is not going to favour that company. When I read an article or hear a talk by a neurologist, I always look to see if there is any disclosure information. Sometimes there is, and the amount and diversity of the monetary transactions between the neurologist and the drug companies is usually very impressive. A few days ago I checked out a video with the inviting title of “The Multidisciplinary Team in Multiple Sclerosis:

Harnessing the Array of Diagnostic and Therapeutic Tools to Improve Quality of Life” and a neurologist named Pat Coyle was the moderator. Not surprisingly, drugs were by far the main topic of discussion and a few other medical practitioners such as psychiatrists were recommended. I could not but help notice that a nutritionist was not part of the “team”.

Of interest, there was a disclosure entry for the moderator, Dr Coyle, and it read like so: “ *Sources of Funding for Research:* Bayer HealthCare Pharmaceuticals; EMD Serono, Inc.; Teva Neuroscience, Inc. *Consulting Agreements:* Bayer HealthCare Pharmaceuticals; Biogen Idec; EMD Serono, Inc.; Pfizer Inc; Sanofi-aventis Group; Teva Neuroscience, Inc. *Speakers' Bureau/Honorarium Agreements:* Bayer HealthCare Pharmaceuticals; Biogen Idec; EMD Serono, Inc.; Pfizer Inc; Teva Neuroscience, Inc. At least Dr Coyle is not choosy who she takes money from and she seems to have hit up most of the big MS drug companies. Given such a compromised position, one should not expect anything written or moderated by her to be anything but drugs, drugs, drugs and to be very biased.

Thus, a newly diagnosed person should expect to receive only somewhat biased information on one or more MS drugs from their neurologist. This has some value because a drug may have some modest benefit. Furthermore, it really doesn't matter which one is recommended because the drugs all seem to have the same low chance of providing some benefit. One unfortunate aspect of the drug discussion is that the neurologist will probably not disclose the likelihood that the recommended drug will only provide modest benefit at best and it may well not provide any benefit at all.

In summary, the main problems for the newly diagnosed with the current situation are that they often leave the neurologist's office thinking an MS drug will prevent any future problems and they do not hear about other therapies. This situation substantially increases the person's risk of ending up with serious disability.

My advice to the newly diagnosed is to take the risks of future problems associated with multiple sclerosis very seriously. Given these risks, they need to dedicate themselves to finding out everything they can about MS, in terms of the disease process, the efficacy of the drugs, and the existence of other potentially beneficial therapies which are backed by solid science. They should not expect their neurologist to help them in this endeavour. They should also not expect their National MS Society to provide such information

because, once again, due to large financial ties with drug companies, these organizations are strongly compromised. Consequently, they studiously avoid a balanced discussion of other therapies.

The good news is there are readily available sources of information which will provide answers to the important questions a newly diagnosed person must ask. Smaller MS charities such as MSRC tend to be much more “client-centred” and can provide a great deal of useful and wide-ranging information in person and on their websites.

Overall, the best sources of information are on the internet, especially sites which are run by persons with MS. One can find descriptions of every imaginable therapy and one must simply test each recommended therapy against the science which is supporting it. Therapies like “zappers” which purport to kill MS-causing parasites and magic potions like “homeopathic snake venom” can be readily dismissed due to a complete lack of science and a strong commercial aspect.

Basically, any therapy that affects the biochemical state of the body should be carefully evaluated because MS is fundamentally a biochemical failure. Thus therapies connected to nutrition, stress relief and exercise all should be considered as having reasonable potential, especially given the fact they are safe and low cost. I can only emphasize the need to check for supporting science and a scientific rationale between the therapy and the MS disease process. Therapies which are expensive and associated only with anecdotal accounts rather than solid scientific facts and arguments are highly suspect and need extra careful investigation.

Because the risk of serious disability is high and the chances for halting MS disease progression decrease with increasing time from diagnosis, the first few years after diagnosis are critical for a newly diagnosed person. They must do as much research as possible (read, read, read) and adopt as many science-backed therapies as possible to try to greatly slow or even halt disease progression. Taking adequate vitamin D is just one example of a safe, very low cost therapy which is backed by overwhelming science. There are many more such therapies available. The newly diagnosed person must accept the fact it is a “do it yourself” project although loved ones and close friends often are glad to help with information gathering. I cannot emphasize enough that it is necessary to be very wary of compromised sources of information where money seems to be the driving force behind the touted therapy.

My most important piece of advice is that the use of an MS drug is fine but one should not depend on a drug therapy to substantially reduce the risk of disability and premature death. One needs to do much more than that to greatly reduce the serious risks associated with having MS. New Pathways is just but one of the great resources out there which provide information on potentially valuable therapies for MS.

Finally, I am pleased to report that a recent study found that 70% of the surveyed individuals were using therapies other than drugs and that they were more satisfied with the results from those therapies than the drug therapy. This is very encouraging and there is no doubt that the improved communication facilities of our modern society are gradually freeing people from the self-serving domination of the medical/pharmaceutical complex.