

## Appendix 8

# WORKING WITH YOUR DOCTOR:

## BUILDING A GOOD RELATIONSHIP

Your doctor may be an all-knowing saint or avatar. On the other hand, he may be a mere human. If the latter, he will tend, like the rest of us humans, to be just a tad defensive, proud, and worried about his professional liabilities. Therefore, if you really want to have a good, working relationship with him, you will start by acknowledging him as a human. You will not, at some time in future, attack him with diatribes based on something you've read in a book. Your doctor is a professional, but he is not necessarily a psychic or able to keep up with all the information available about Parkinson's. There is a very good chance that he is being the best doctor he knows how to be.

When it comes to Parkinson's medications, while you need to be aware that he is probably un- or misinformed, it is not your place to educate your doctor. He must work within the Standard of Care for his profession, no matter how many clippings you bring him showing him that he is wrong.

That having been said, the single most common problem that my patients have had with their doctors comes from the MDs' resentment towards patients' "insubordination," patients' refusal to follow orders unquestioningly, right or wrong.

### *Be aware of your rights.*

Doctors do not have the right to tell you what you must do. Their prescriptions are only suggestions – so long as you are competent and not a danger to yourself or others, you have the right to use medications or not. However, many doctors, for noble reasons or lowly, decide that their duty is to command and yours is to follow. Therefore, if your doctor is of this type, you may wish to placate him. He is, after all, only human. Then again, you may need to change doctors.

If you, on your own, decide that you wish to reduce your medication, you are implying that the doctor has made a mistake. No one likes to be told that they made a mistake. My patients tried various methods of vocabulary to avoid hurting their doctors' feelings while informing the doc that they were reducing medications, but we have found that only one method was universally successful.

### *Doctors respect hallucinations*

As noted in the text, the advent of hallucinations was the one sure method of receiving doctor support for reducing medications. During the three years while Hjalmar had been getting treated by me and reducing his medication, he had seen his neurologist every six months. Dr. Rafferty had praised him for how well he was moving, and asked him what he was doing differently. The first time, Hjalmar said "Acupuncture." Dr. Rafferty laughed and said, "No, really, what are you doing?" Six months later, when Hjalmar again answered the question with "acupuncture," Rafferty laughed again, and said, "Your wife sure is taking good care of you." This happened again six months later.

When, six months later still, Dr. Rafferty asked him for the fourth time, “What’s your secret? You’re doing so well! Do you have any advice for my practice?” Hjalmar thought for a moment, then suggested, “Keep practicing.” (Hjalmar was very proud of this crack, and retold it to me many times. Hjalmar was just starting to feel bitterness towards his good doctor of more than twenty years – he was giving the doctor honest, truthful input, and the doctor every time simply assumed that Hjalmar was joking.)<sup>1</sup>

Every time that Hjalmar reduced his medication, the doctor asked why. Sophia, Hjalmar’s wife, always said that it was because Hjalmar was having hallucinations. It was Sophia, by the way, who first discovered the power of the hallucinations argument. We were to find later that no matter how well a patient was doing on lowered drugs, even if he was in better shape than he was at a higher dosage, most doctors, especially the ones educated in the 1970’s and 1980’s, would get a bit huffy if you told them the medications had been reduced. This was an implication that the doctor had prescribed the wrong amount, I suppose. Sophia first, and then others, found out that if you said the meds had to be reduced because the patient was having hallucinations, the doctor would always agree to the reduction.

It was as if the doctors didn’t care about the dyskinesia, and they were inured to the stories of insomnia and agitation, altered personality, and the rest. They considered that to be a part of the worsening Parkinson’s. The solution to all of those symptoms was to increase the medication. But hallucinations? Those were Bad. For some reason, all the neuros that we have heard about in this program in five years seem to agree: it is reasonable to reduce the medications in cases of hallucinations. No other reason is particularly valid. Hallucinations were the magic line of side effects over which the doctors would not cross. And so as Hjalmar continued reducing his medication, glimpses of his old self became more frequent, his agitation decreased, and his doctor continued to support him.

I must note, one MD in our experience, Zoe’s doctor, didn’t care about hallucinations. He felt that, in some cases, any decrease in L-dopa could precipitate fatal seizures, and that “you can still be alive with hallucinations, but not with seizures.”

### ***A word you maybe shouldn’t use with your doctor***

Iatrogenesis (ee a truh JE nuh sis): “the creation of illness and injury in patients as a result of medical treatment. From the Greek: *iatro*, *doctor* + *genesis*, *produced or generated by*.

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<sup>1</sup> I sent Dr. Rafferty a form asking with regard to a list of specific symptoms whether Hjalmar was worse, the same, or improved, since 1998 (when Hjalmar started the project). The list included symptoms such as falling down (which he was no longer doing, and which he had previously done several times a day), volume of speaking voice (he had had no voice when we started, and the voice had returned), ability to straighten the fingers (his fingers had been unusable when we started), and so on. The MD had returned the form with “same” checked off in every box. Considering that Hjalmar had improved in every area (of course, we had purposely written up the form to play up his improvements), and had reduced his meds (at that time) to less than one third of what they had been, this response was very upsetting to both Hjalmar and Sophia. They felt betrayed. They had told the doctor that Hjalmar was doing well, and for two years the doctor had expressed amazement at his improvements. But this man refused to put it in writing. At any rate, the doctor has written that everything was the same. Considering that the disease is supposedly incurable, and that Hjalmar had reduced his medication by two thirds, I decided that even the statement that “everything was the same” was something of a victory. I wrote the doctor a thank-you note for his statement of support for our project. He did not answer.

“There is a long list of iatrogenic diseases – those induced by physicians and by the drugs, vaccines, and other new therapies they use. Certain anemias have resulted as a complication of the surgical insertion of artificial heart valves, for example. Such diseases are essentially diseases of medical progress. They would not have occurred in the days when doctors could do little beyond prescribing worthless medications and holding the hands of patients as they died. Today many therapies actually work, but their undesired effects make them double-edged swords.”<sup>1</sup>

### ***Doctors in the dark***

As promised in an earlier appendix, here is information from an article from the *Journal of the American Medical Association* (JAMA) that arrived recently (February 2003) from my neurology weblines:

“Clinical Practice Lags Behind Medical Research”

The title says it all. But if you want details, the gist of this article from the Clinical Research Roundtable is that research findings don’t always make the transition into practical application. Here are some excerpts:

“Despite the proliferation of medical research, much of this new information is not affecting clinical practice...(and) findings of clinical studies are slow to influence medical practice and healthcare policy. Factors contributing to these translational blocks include high costs, slow results, lack of funding, regulatory burdens, fragmented infrastructure, incompatible databases, and not enough qualified investigators or willing subjects...”

“In an accompanying editorial, Roger N. Rosenburg, MD, from the University of Texas Southwestern Medical Center in Dallas, suggests that one solution might be to establish a Department of Biomedical Research analogous to the Department of Homeland Security. ‘A unified voice from the biomedical community must speak clearly and resolutely to emphasize that the CRR (Clinical Research Roundtable) report [on clinical practice not matching research] amounts to a national crisis,’ he writes. “The American people need to know that the current system for bringing ...research to the bedside is operating at an obsolete level of efficiency, causing great delay, and consequently resulting in the loss of many lives.”

Later in the article, Dr. Sung, PhD, program officer of the Burroughs Wellcome Fund in Research Triangle Park, N. Carolina, responded to the questions posed by Medscape.

“Clinical studies...in many cases, are only sporadically applied to the patients who need them. Where strong evidence-based practice guidelines exist, they are frequently not followed by physicians and other practitioners. Comparative data on the effectiveness of old versus new technologies is often lacking...consequently, significant holes exist in the body of evidence from which clinicians [doctors and nurses who actually treat patients, as opposed to researchers] and consumers base health promotion and treatment decisions, and on which health plans and employers make coverage decisions...”

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<sup>1</sup> Greenman, Robert. *Words That Make a Difference*, Levenger Press, Delray Beach, Florida, 2002, p 181.

“Insurance benefits may limit coverage inadvertently by placing some new and potentially better...therapeutic interventions out of reach of ordinary consumers. Conversely, benefits may include coverage for therapies that are of questionable value or have even been proven ineffective. These problems will become more acute as the pace of medical and health sciences innovation quickens...”

“The clinical research enterprise presently contains inefficiencies at almost every step. We lack data on the numbers of adverse events or the denominator of how many are actually enrolled in clinical studies...Most medical records are kept manually. Clinical research staff are often overtaxed. Replicated entry of data on charts, insurance claim forms, clinical trial forms, and adverse event forms is the rule...

“Standardization (an electronic record keeping) in other industries has facilitated vast savings through process improvement, and information technology has been an integral part of this transformation. This same revolution has yet to happen in healthcare – indeed, the entire healthcare industry continues to invest significantly less in information technology than any other information-intensive industry.”<sup>1</sup>

Although the person interviewed in the above article blames the problem on funding and lack of standardization in record keeping, a large part of the problem may actually be the human component: the psychological resistance of people – even doctors – to a change in their status quo.

There is no legal requirement that doctors be up-to-date, or that they modify their treatments from what they learned in school thirty years earlier. The continuing education requirements only require that doctors take classes, but not necessarily classes in clinical application in their own field. Current medical certification does not require that a doctor be regularly tested on his rapidly-changing area of expertise. But as demonstrated in the International Parkinson’s conference, even doctors who do try to keep up often decide to ignore the new findings. This human tendency for inertia, more than any amount of funding, may be the reason that so few doctors, including “top authorities,” are actually up to date in their field.

Finally, remember that a person gets to be a “top authority” by producing a smidgeon of new data early in his career. In hopes of being someday honored by his finding, his job is to defend his data and its conclusion against all comers during the following decades. If his data becomes outmoded or proved wrong, his findings will be sneered at and his status reduced. The current system only allows a person to become a “top authority” *if* his previous work remains unchallenged. If you are working with a top authority, you are most likely working with a person who is desperately trying to maintain the status quo and force all subsequent research to conform to his own previous contribution.

### ***A little something for your doctor.***

Here is an example of the articles that cross my desk regularly. The gist of this one is that mice were brain damaged via a chemical that kills dopamine-producing cells. They were then given levodopa. Over time, some of them developed dyskinesias. The ones with dyskinesias were seen to have damage to certain nerve synapses (nerve

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<sup>1</sup> *JAMA*. 2003; 289:1278-1287. 1305-1306.

junctions). The drug that caused the cell death didn't cause the nerve synapse damage – the levodopa did. The conclusion is that levodopa, although helping to give movement to dopamine-deficient mice, also causes damage, and there is an association with the damage and dyskinesia. The damage was associated with dyskinesia. Dear reader, do not jump to a cause and effect conclusion! That would probably result in bad science. Whether damage or the dyskinesia came first is not known. Nor is it known if the mice had equal amounts of original brain damage, so that the levodopa was more or less excessive in some mice than in others.

However, a relationship has been seen between levodopa, brain nerve damage, and dyskinesia. This is merely an example of the sort of research that is available and which shows that doctors who attribute dyskinesia to advancing Parkinson's may be wrong. Your doctor may appreciate, or may not, knowing that there is new information on this subject. Here is an excerpt from the article.

“L-DOPA Dyskinesia Linked to Reduced Plasticity of Corticostriatal Synapses”  
source: Reuters Health Information, April 4 (2003).

“Levodopa (L-DOPA)-induced dyskinesia is associated with reduced synaptic plasticity in the corticostriatal pathway in a rat model of Parkinson's disease. According to a report in *Nature Neuroscience*, published online March 31st, maintenance or restoration of synaptic plasticity represents a potential therapeutic target for these patients.

“Even though L-DOPA is considered the most effective therapy for Parkinson's disease, long-term treatment often results in the gradual development of dyskinesia. According to Dr. Paolo Calabresi, of the University of Rome, and associates, this complication may be caused by overactivity of the striatal output pathways [due to the levodopa].

"A lack of depotentiation of corticostriatal inputs may have profound pathophysiological consequences in Parkinson's disease patients treated with L-DOPA," the investigators conclude.

In basic English, L-dopa causes damage in the substantia nigra.

### ***Educating your doctor***

Whether or not you want to learn to read articles like the above and foist them off on your doctor, who, if he is normal, will not alter his prescribing patterns regardless of the new findings, is up to you. But I included the above just as an example of the research that is available that makes the point that levodopa causes brain damage. Enjoy.

### ***Educating your patient***

For the benefit of all the non-MD health care practitioners who might be reading this book, I will tell you what I did for my patients. I read out loud. I read to them from the *Physician's Drug Handbook*. I read them the lists of adverse effects from their drug inserts. I read to them out loud the correct dosages of the drugs, which often conflicted with their prescribed doses. I read to them the warnings about the drugs.

Sometimes I would read the list of side effects to patients several weeks in a row because each week they would fixate on the symptoms that matched their problems that particular week, and then the next week, they couldn't understand the new symptoms that

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appeared. Sometimes my patients were so well informed that they told me how they were going to determine which of their drugs to decrease next, based on their changed side effects.

You cannot tell a patient what to do with his meds unless you are an MD. I am not an MD. But I'm pleased to say that my patients now know the published, legally available information about their medications better than their MDs. They needed to know this in order to take the correct amount of medications. I also shared with patients what we were finding with other cases. Every week, nearly every medicated patient would be told about what the other patients (unnamed) were noticing with their medication changes. And there was a lot to talk about.

Do remember to observe patient confidentiality. If you only have two Parkinson's patients, you may not be able to make suggestions based on your experience with your other patient, as the patients may know each other. You may wish to use the case studies in this book, instead, for your examples.

Never say that you will work with a patient on the condition that he first stops taking medication. To do so is to make prescriptive advice about the drugs; you are saying, in essence, that he should stop taking drugs – you have no right to say that. If you are willing to take my advice, you will simply not work with medicated patients, period. Do not enter into negotiations and do not make suggestions. You do not have the right to do so. If you are not an MD and you make suggestions about the drugs, you will be violating the law, and certainly, if you lose your license, you may not be working in the patient's best interest. It is not in the best interest of the world for compassionate health care professionals to lose their licenses.

While the refusal to treat a medicated PD patient may seem rather harsh on those people who are currently taking antiparkinson's medications, working with them may prove to be a false kindness.