

Dr. Osmond's Memos

Beginning with this issue, the Journal will carry a brief section entitled "Dr. Osmond's Memos." For over 20 years Dr. Osmond has engaged in a wide range of correspondence with a large number of scientists, physicians, psychiatrists, and eminent men in philosophy and the Arts.

As a recipient of his memos for many years, it occurred to me that while all of his memos should be widely circulated, some have such a special relationship to treatment of patients that readers of this Journal should have an opportunity of seeing them and considering the points made therein. The memos will be selected by me, and will appear unedited or with only minor editorial changes. Any reader may submit points of agreement or disagreement and some of their letters may be published here.

A. Hoffer, M.D., Ph.D Managing Editor
THE OTHER END OF THE STETHOSCOPE

Roger MacDougall¹

"Although there's not much pain in it, Multiple Sclerosis is no bed of roses. I know, I've lain in it."

Being at the wrong end of a stethoscope can be an unpleasant experience for the over-imaginative. Being at the wrong end of a neurologist's little rubber hammer is an experience I found to be even more trying. And when I was asked to think about peaceful scenes like a glorious summer's day at the beach, or a pastorally symphonic farmyard scene with Devon cattle lowing and barnyard fowls crowing and clucking, while I was at the receiving end of a syringe which that

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same neurologist was sticking into my spine, my mind, as they say, boggled. That was not a time for thinking beautiful, peaceful thoughts. That was a time for thinking cowardly, panic-stricken certainties of death and graveyards and coffins.

That man was sucking out my spinal fluid and making calculations to determine whether I had a tumour in the brain or merely an attack of some lethal neurological disease. And he was asking me to think about peaceful summer days. That man was a maniac. And a dangerous maniac.

These were my thoughts as I submitted to a diagnosis at Queen Square Hospital, just over 20 years ago. And I have never had occasion to go back on them.

Because I was terrified and helpless, I stayed with my tormentors for four years. Every so often I was taken in to have some new indignity perpetrated on me. A transfusion of fresh blood! A course of arsenic poisoning! (True.) And then, after four years, I summoned up enough courage to leave them for good.

I had become sufficiently inured to my state of purblindness and near paralysis, to be able to think more clearly about the whole wretched business and, thinking clearly, it was obvious that these learned gentlemen were stumbling about in the dark and hadn't a blind idea where they were going — bumping into each other, bumping into their patients, in a ludicrous game of blind man's buff. I decided that was a game I had outgrown.

And that was the best decision I ever came to in my whole life, because while they are still lurching around at their pathetic little parlour game, pretending to write erudite papers on the subject of neurology, pretending to look after the unfortunate little flies who became entangled in their web, here am I, 100 per cent fit again (not cured but stabilized) as healthy as any 62-year-old with thousands of unfortunates following in my footsteps and beginning to feel the benefit.

Are these gentlemen aware of what has happened to me? Of course they are aware of

what has happened to me. I've told them, and, a year ago, one of their number came to examine me.

He found vestigial traces of multiple sclerosis in some obscure nerve located near my right heel, but not much else. He was puzzled. I could see he was puzzled. And subsequent events proved that official complacency had been somewhat shattered.

Investigations into a gluten-free diet have been set up in Manchester, Edinburgh, and Ulster. So that now when people write to the MS Society to ask what is known about my diet, the MS Society can proudly say that its possible efficacy is being tested.

And, as you might guess, this is not true. The efficacy of my diet is based on the assumption that while gluten is one of the causes, certain deficiencies are equally important. And a gluten-free diet is usually achieved with the loss of a certain amount of vitamin B which happens to be already one of the principle deficiencies. The test that is being conducted might produce negative results.

If I've written one letter to point this out, I've written 20. But communication up the stethoscope seems to be impossible. In these matters, the stethoscope is a one way instrument. It can hear the murmuring of your heart, but it seems to be totally unable to hear the shrill, urgent alarm calls of your voice.

I've been shouting up that stethoscope for more than a year now, shouting until I'm hoarse, and worse, shouting until I've become a compulsive shouter up stethoscopes.

This invokes a far from impossible picture of me running amok in a hospital, grabbing all the stethoscopes I see in use and shouting up them — first pleas for sanity and finally, no doubt, garbled messages of combined abuse and obscenity until I'm taken away, raving, and put in a straitjacket.

Now that I've thought of it, I'm certain that's going to be my end. You see I, a lonely,

unprotected layman, have taken on the Establishment. And that is an unforgivable piece of effrontery. For that, I will be punished. I am a marked man. I will be pursued by doctors. Worse, by surgeons, who will rally to the support of their colleagues, sharpen their scalpels, and join in the chase.

I have committed the unpardonable sin. I have shown up their inadequacy. I'm like a man on trial for his life who has dismissed his lawyers, conducted his own case, and won a total pardon. Would he be popular with his lawyers?

Think then of how I will be treated by the medicos. You see, I've found the fallacy in their thinking.

I didn't recover by accident. I recovered by using logic where a doctor uses aetiology, and logic is the superior weapon.

I managed to get myself sufficiently calm to take a cold, cool look at the problem and because I am not blinded by an excess of unnecessary knowledge I managed to see through to the solution, at least in theory.

When I put the theory into practice, it worked. Many thousands of people in 25 different countries are also putting it into practice. Few of them have been on the diet for long enough yet to see tangible results, but already 40 or 50 are feeling the benefit, some in quite a spectacular way.

There was a "Do it Yourself" craze in America when I was there last. It's a temptation to say to people, "To hell with your neurologists, join me and the 'do it yourself bunch'," but I mustn't. It would be easy of course. I've never met anyone who had a good word to say for his neurologist. Next to hangmen, bailiffs, and dentists, they must be the most unpopular professionals there are. And when I think of it, so long as he doesn't abandon his doctor, there's no harm whatsoever in a patient saying goodbye to his neurologist. None.

MS really has nothing to do with neurology

or neurologists. It's an enteropathic disease. I can see a neurologist sticking a syringe into me and <sucking out more than my spinal fluid. But I can't go on shouting up stethoscopes till I die. If I can't make myself heard that way, I have to try elsewhere.

Though I may sound flippant, I'm in deadly earnest. I can produce chapter and verse for everything I say. And if I'm accused of giving false hope then I really will flip my lid.

That "false hope" lark is the oldest trick in the doctor's bag. Have you ever heard of anyone suffering from an incurable disease who objected to a little hope? I suffered from an incurable disease and I longed for it. I've had thousands upon thousands of letters from MS sufferers and hardly one fails to mention the ray of hope. "Even if it doesn't work for me," they'll say, "how wonderful it is to be doing something that just might work, after the undiluted pessimism of the doctors and specialists."

That is standard. People would rather be trying something, anything than doing nothing. That's obvious. And what am I asking them to do? Take a healthy diet with a "crash" supplement of vitamins and minerals. You'd think I was asking them to swallow arsenic — as my specialist asked me.

The power of the Medical Profession is such that they actually make me feel guilty about telling people I've managed to recover from MS. I feel somehow that I've committed an unclean act. I'm a pariah. I should be cast out from society, with the entire General Medical Council lined up in frock coats pointing fingers of scorn at me.

Would it help matters if I made a public apology?

To whom it may concern: "I hereby solemnly promise that I will never again interfere with the inability of neurologists to cope with my MS but will be happy to remain a contented cabbage in a wheel chair unable to read or write. Sorry I can't sign. I can't even hold a pencil."

INCURABLE DISEASES

Humphry Osmond, M.R.C.P., F.R.C.Psych.

Neurology generally is inclined to attract those with Sherlock Holmes-like minds for whom diagnosis is more fascinating than treatment. Indeed there frequently is no treatment of agreed efficacy. This leads to and also encourages a certain kind of detachment among neurologists which, while understandable, is not especially cheering for patients.

Mr. MacDougall is certainly correct — I don't think that it is quite the matter of showing up inadequacy which jolts neurologists — but it is that he has got well against the rules. This is just as vexing as dying against the rules. Both are equally unwelcome events to doctors, although patients might feel that the latter was worse than the former. I don't think this is necessarily so for doctors. What Mr. MacDougall has done, I suspect, is not to make his neurologist suppose that he has got well but to call in question the diagnosis! Since this was made at Queen Square it is a very awkward and also embarrassing business.

I think that it is very interesting that the MS Society, like the CMHA in Canada and NIMH in the United States, seems reluctant to start by exactly replicating what MacDougall said that he did. What they want to do quite evidently is to fragment his treatment because that would be more "scientific." I seem to have come across this before! I think that his "false hope" bit is especially apt and similar to what we find in schizophrenia.

I had a letter today from someone whose schizophrenic son was delighted, but also astonished, to find that some people (about 30 to 40 percent) recover spontaneously. He had never heard about this, and this is one way to discourage people.

I think that this very lively little piece has a further lesson for us, which has much bearing on schizophrenia, alcoholism, etc. Neurology shows it up elegantly because neurologists have come very close to subscribing to an aspect of

the science model due to the modesty of their therapeutic successes.

The objections to MacDougall's procedures are based upon the fact that they might generate "false hope," not that they might do harm. These are much the same objections voiced by Lipton, Kety et al. As MacDougall emphasizes, given the choice between no hope at all and "false hope," most people will choose "false hope," especially if there is at least some evidence that even one person has got better.

The question arises as to who is right, those who stoically refuse to generate any "false hopes" or those who take that grievous risk? I don't believe that this is an academic matter. Doctors who are very zealous about never generating "false hopes," as we have shown with schizophrenia, frequently cease to give out wholly accepted and well-known hope-carrying information! This has actually resulted in people being denied cheering news. It has also made psychiatrists unwilling to try new approaches and, regarding megavitamins especially, has edged them into breaking Claude Bernard's rules as regards clinical experiment. This becomes very clear with the APA's approach. Their view is that one does not use treatments until one has proof of efficacy, but what such proof may be and what treatments meet this standard is not discussed. This does not happen to be Bernard's approach and few would deny that he was a better scientist than any of the APA's Task Force. What he said, as I recall, was that treatments that may help, and are unlikely to harm, are obligatory. We should naturally quote his exact words.

What has happened with the APA and MacDougall's neurologists is simple — but bizarre, for as Osier emphasized in the clinical model, you never dispense with hope while there is life. This does not necessarily mean keeping the moribund alive or semi-alive, but in schizophrenia few patients are moribund. What the APA and the neurologists have done is to set an arbitrary but undefined standard for which they claim "legitimate hope," and anything below that

standard becomes "false hope." It is an interesting manoeuvre — but it is not in accord with Bernard's rules and I doubt whether it is for the patients' good. Doctors as squeamish about giving hope as the APA Task Force should surely ask whether patients agree with their supposedly rigorous standards. Perhaps some patients would not object to hope even at 5:1, 10:1, 25:1, or 100:1 against? Have these purists inquired?

In the "science model" of medicine, as Renee Fox showed in her *Experiment Perilous*, patients are seldom asked their views about the experimental process. It is usually assumed, often quite mistakenly, that they are not interested or not concerned. This is simply untrue. However, it is necessary to be sure whether the experiment is being conducted in terms of the science or the clinical models of medicine.

The recent discussions of the Tusagee affair (in which the syphilis treatments available in the early 1930's were withheld from a number of poor black men) suggests that much confusion exists regarding clinical and scientific experiments. The Marlboro niacin study appears to have run into similar difficulties. It is now not at all clear that patients agreed to have placebo!

From our point of view, Roger Mac-Dougall's article is a discussion of patients' rights regarding illnesses in which medicine, for whatever reason, has ceased to offer hope, or in which treatment is dangerous, repugnant, or worse than no treatment.

I believe that an examination of Bernard's rules in this context would be extremely useful. Many doctors do not distinguish between treatments, regimens, etc. with which they do not happen to agree, and the likelihood of such activities helping or harming the patient. This often results in attempts to impose a regimen which is more damaging than none. An example here was Lenin whose doctors would only let him dictate for five to 10 minutes a day. He obeyed on the whole, but was enormously frustrated by the regimen which may have done more harm than good.

What we need is a combination of Bernard's rules and Baillie's new approach set in the context of the sick role, Aesculapian Authority, and the clinical model. We also need both doctors and patients to be aware that the rules are flexible and change with the nature of the illness and the particular treatments, or lack of them, at a particular time.

It seems unlikely that during their medical training most doctors devote much time to such considerations which have much bearing on their relationship to patients as responsible participants in the battle against illness. Roger MacDougall is a Tito or a Mao among patients, and not all regulars have the sense to learn from guerillas, but it has been known to happen, as with the discovery of digitalis by William Withering.