

# BOOK REVIEW

## LIVING WITH MYSTERIOUS EPILEPSY

**Ruth C. Adams, Exposition Press, New York**

Ever since I read Dr. Walter C. Alvarez's classic **Nervousness, Indigestion and Pain** in a small ship at sea in the 1940's, I have been a devoted admirer of this great doctor. He has now edited a series of letters from a patient which covers the last 10 years of her life when she was being treated by him for a largely non-convulsive epilepsy which, up to that time, had been wholly neglected due to misdiagnosis. In his introduction, he points out that in one series of his own containing more than 250 people all of whom proved to have non-convulsive epilepsy, not one of them had been diagnosed correctly, yet this is no new illness for Hippocrates wrote about it 400 years before Christ. Dr. Hulan Jackson published two volumes regarding it during the 1890's, and he is considered to be one of the greatest neurological clinicians who ever lived, while other notable epileptologists like Dr. William Lenox, Prof. Frederick Gibbs, and Dr. Stanley Cobb all agreed that this is a frequent disorder. Frequent it may be, but it appears to be even more frequently missed. Prof. Gibbs told Dr. Alvarez that for every epileptic he sees with convulsions, he sees 10 without them. Dr. Alvarez points out that since there are at least a million easily recognizable epileptics in America then, if Prof. Gibbs and Cobb are right, there must be several more million unfortunates who could be greatly helped, particularly with the use of dilantin.

Ruth Adams, the author of this book, consulted him when she was 48 after having seen many psychiatrists, received a great deal of psychotherapy and many shock treatments.

It appears that she had had disturbance of consciousness, itchings, and episodes of violent temper, great fear, confusion, depression, and hallucination since the age of six. Her family's story suggests that a number of her close relatives were similarly afflicted. In addition to her non-convulsive epilepsy which had made her life a great burden, Ruth Adams also suffered from high blood pressure. It is truly remarkable that she had managed to keep going and become a well-qualified nurse in spite of frequent and distressing epileptic phenomena.

Ruth's letters began after her first visit to Dr. Alvarez and she continued writing them for the rest of her life until shortly before her death from the result of a stroke almost 10 years later. She came to see him because she was desperate, fearing that she might wind up in a mental hospital, and she kept wondering what was the basic cause for her spells of twitching and jerking. Dr. Alvarez notes, "I have found with many patients as with Ruth, that my telling them the truth about their illness, even if the truth is distressing, brings them peace of mind and comfort." Since he had been practicing medicine for at least 60 years, those with less experience than he might be well advised to take note of this succinct statement based on enormous experience.

Ruth quickly obtained much benefit from the dilantin, but throughout the letters it becomes clear enough that one of

the main problems was to persuade her to continue taking an adequate amount of medicine. Not only did she frequently go off her medicine, but, in addition to this, she often took less\* than had been prescribed. It would appear that her fears of psychotherapy had done much to make it hard for her to occupy the sick role and, although she was clearly much impressed by Dr. Alvarez's formidable Aesculapian authority, she was still not wholly clear about her obligations as a good patient. This, curiously enough, in spite of the fact that she was an able nurse and that this treatment did more for her than any that she had had during the rest of her lifetime. However, early in the letters, we find that Ruth has learned how to recognize events that were in her mind and that she gradually discovers that anger is frequently followed by a spell of increased epileptic phenomena.

Oddly enough, she never seems to have thought that after becoming angry she might take an extra dilantin for she was nearly always undertreating herself, seldom carrying out Dr. Alvarez's instructions to the letter. Within a few months, she is describing how much easier she feels taking dilantin of which she says, "Your dilantin has let down bars of fear. I work alone on duty trusted and without the old anger. I can ask for advice or discussion any time. This is heaven. I couldn't stand it before day after day. People saying, 'Do it just so.' But with this medicine, I find I am conforming to routine without pressure."

Ruth has an extraordinary description of one of these changes of consciousness produced by epilepsy, before she was taking dilantin. "One night in the hall, suddenly all was dark. I remember standing still frightened and knowing I must not scream (p. 27)—the wall I faced was covered with what I thought was grapevines and, through these vines, hundreds of black piercing eyes glared at me. How long it lasted, I don't know. Then the hall light was burning again as usual. I pulled myself together and

\* There is a good deal of evidence that while overuse of drugs in a domestic way is one problem, underuse by patients who are ill is an equally serious and more neglected one.

decided I was on the verge of a bad breakdown. I buried the experience deep in my mind and never spoke about it. It was some three months before I was over my fear of that hallway."

This reminds me of a curious experience when I visited a well-known English mental hospital accompanying a patient who was going to be admitted there. When I reached the desk, I was astonished to find that the hallway in which it stood was covered with an elaborate wallpaper depicting a huge grapevine covered with grapes. Every so often among the grapes, one could see an eye peering out. It is difficult to imagine any less suitable decor for a psychiatric hospital.

One consequence of Ruth's not taking her medicine very regularly was that her brain disturbances would recur, making life very difficult for her. For instance (p. 29 bottom), she describes a curious episode, "Tonight as I talked with a patient, a hallucination appeared. I saw an immense set of dentures dangling from fine wires. I went home as soon as I could. I know I must learn to accept problems and responsibilities and especially to get along with people." One of the advantages of these letters, and of the writings of other mentally ill people, is that they allow us, should we wish to do so, to ask ourselves how we would behave in circumstances similar to those which Ruth had endured for year after year. She exhibited great self-control here for this must have been very frightening. About the only advantage of such a bizarre hallucination is that one is more likely to recognize it for what it is — it is the subtle distortions of perception which frequently produce distressing social results even among people who are as courageous as Ruth.

In spite of the excellent effects of dilantin, Ruth still continued to have minor attacks which resulted in transient losses of consciousness and little injuries which made life very difficult for her.

Ruth's early life was far from easy. Her home was an unhappy one; she was very shortsighted — she was as we now know suffering from non-convulsive epilepsy, and several other members of her family

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were also ill. Presumably, then, as in her later years, she had considerable difficulty in deciding what was really happening and what was the result of her disturbed consciousness in perception produced by her illness, which was not, of course, recognized until the last 10 years of her life.

This book is crammed with interesting descriptions of psychopathological phenomena from the inside. One, page 40, is a description of thought disorder. It says, "One day on duty, I couldn't use the correct words to make a sentence. I was confused and my thoughts were mixed-up like a crossword puzzle before it is worked out." By this time, she is already beginning to develop insight, and she says, "Occasionally, I hear voices, but now, since I know it is my brain acting up, I don't worry." There are many examples in this book of the terrors endured by one subjected to repeated hallucinatory experiences. Anyone working with mentally ill people should read Ruth's admirable account of them and will, perhaps, be less inclined to brush off their patients with some ready-made explanation. Many patients will accept the fact that these are peculiar expressions of the workings of their brain requiring all their courage, intelligence, and resourcefulness to recognize them for what they are.

Ruth's illness reproduces most of the symptoms of schizophrenia, the main difference, I suppose, being that these were episodic rather than continuous. She described, for instance, an out-of-the-body experience (p. 49), "I woke up at 4:00 a.m. I lay quiet and it seemed to me I left my body on the bed while my mind walked out. I seemed to be on a lovely sunlit street. My mind came back, and I was ready to take my body out of the bed. Now my mind is getting blank and I don't know what I want it to say." Ruth mentions a form of self-treatment which may be helpful to many people since it is one of the best and most easily accessible tranquilizers. She says, "When I get too excited, I try to stay in a bath." Hydrotherapy was, at one time, possibly rather overrated, but I think we have gone to the other extreme now, and people who

might get great benefit from a long warm bath as an anti-tension agent are seldom told about this, but Ruth seems to have discovered it for herself.

Dr. Alvarez had encouraged her to write these letters, pointing out to her that they would be a help to other people, and they certainly should be, and also that they reminded her that she had pledged herself not to attempt suicide which she had done before she began the dilantin treatment. The letters served to remind her of this promise.

After nearly two years, it is clear that Ruth is beginning to learn that if she gets upset and fatigued she will get worse, and that sometimes this can be headed off by taking an extra dose of dilantin. Nevertheless, in spite of her improvement, her life is often terrifying. She writes, "When I was at home alone visiting with my niece, I looked at the kitchen light and I thought, why not make an end for two? I realized that I had these thoughts in my mind, but I feel I can control myself."

Ruth's earlier indoctrination in models other than the medical had rather unfortunate effects. She writes, for instance, "I have made up my mind no more trying to go without my medicine. When I get down on it, I am mentally lost." Alvarez comments, "Many patients get into trouble by always trying to cut down on the amount of much needed medicine they take. Ruth would be much better off if regularly every day she had taken the four dilantin capsules I had prescribed but said she didn't want to get dependent on the medicine."

This is clearly one of the major differences between the medical and other models. In the medical model, it is one's duty to take the medicine—it is one's doctor's duty to decide whether one is becoming dependent or not. Ruth's trouble was that she was not dependent enough even with Dr. Alvarez's admirable authority which she greatly respected—she tended to see her necessary treatment as a crutch or support to be abandoned as quickly as possible. This grave misunderstanding has caused Ruth and, indeed, many other patients much quite unnecessary suffering.

As one might expect, the book is a gold mine of symptoms of non-convulsive epilepsy Ruth writes, "My body jumped so suddenly, I am thrown off my feet, and I don't know what happens." And Dr. Alvarez notes, "Often I diagnose epilepsy from this story."

Since, through the pages, this question of stopping her medicine is followed by such comments as "I can often see the difference dilantin and neboral make in me," Dr. Alvarez muses, "Often I think how strange it is that many people keep stopping the taking of their medicine long after they have seen that they pay heavily for that." I suspect that, at least in Ruth's case, the problem was that in spite of her great admiration for Dr. Alvarez's Aesculapian authority, she still had not fully accepted the sick role. It is probable that he never made her rights and duties explicit, the reason for this being that, brought up in an age when everyone understood the sick role, it would be difficult for him to believe that there might be some people around today who really do not. I suspect that Ruth would have been much helped by very explicit statements and perhaps even making some sort of contract with her that her part of the bargain was to take her medicine regularly.

Since she was very touchy and difficult, this would involve problems. But it seems likely that if it was made in a friendly and ceremonious way from someone she admired as much as Dr. Alvarez, it might have kept her from these repeated mistakes.

Every so often, a comment comes in one of her letters like this, "Doctor, you are right, when I decrease the dosage of dilantin, my brain acts up."

Ruth wanted her story to help hundreds of thousands of fellow-sufferers, and if they and others read her book, as I hope they will, it may be that some of them will learn from her and not follow her unfortunate example of failing to take her medicine as directed. It is not so clear why Ruth cut back the medicine, but every time she did, she suffered for it. Even though she was able to write, "It's always amazing to me the change that comes in me when I take an extra dose or two

of dilantin. Then I feel wonderful—all my problems then clear up. I seem to be able to work with a clearer head and I don't feel irritable and hysterical," it is sad to realize that in spite of the great benefits from dilantin, most of the time Ruth was undoubtedly taking far less than had been prescribed and than she needed. At a time when there is much talk about overmedication, it is well to remember that great damage can be done by undermedication.

Dr. Alvarez's comments in the text are fascinating and give the book an added dimension. Here, for instance, he remarks, "When I want to learn how well adjusted a patient and his relatives are, I ask him how he likes his relatives and if he says, 'They are all bastards,' I know that they are bad-tempered and lacking in self-control and probably in some serious hereditary trouble." A very useful clinical tip from a great doctor.

Ruth undoubtedly suffered when she was overstimulated, and this is something which apparently epileptics and schizophrenics would do well to avoid. They are seldom, however, given any clear direction as to the kind of situations where overstimulation is liable to occur.

It would be a great service to large numbers of patients if some kind of list of situations to avoid could be compiled so as to remind them where to look out for trouble. Ruth's life remained a stormy one up to the end. She developed a series of strokes and, most unfortunately, when she was in hospital for these, it seems that her dilantin was stopped so that she became a good deal iller with her epilepsy. Dr. Alvarez comments rather sadly, "As usual, when Ruth was in the hospital, the doctors did not give her the necessary anticonvulsive drugs." She continued to write to Dr. Alvarez almost to the very end of her life—her last letter coming on the 25th of March, 1965, and she died on April 1. She wrote these letters in the hope that others would get help from them. Let us hope that her hopes will be justified.

However, quite apart from benefits which may accrue to patients who

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recognize their illness in the mirror of Ruth's suffering, I would hope that this book would be widely read by medical students, nursing students, and others likely to encounter epilepsy in their professional lives, so that they may acquaint themselves with this formidable illness from the inside. Ruth's last 10 years were made much less uncomfortable due to Dr. Alvarez's good advice, but one cannot help wondering what her life would have been like had she met him if she was, say, only six years old and the illness began. It would I think have been a very different story. There must be thousands of Ruths today as much in need as she was then ... if only a few hundred of them are helped by this book, then it will indeed be a tribute to her courageous struggle against her illness.

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