

DR. OSMOND'S MEMOS

PROBLEMS OF ACQUIRING THE SICK ROLE

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Stroke
by Douglas Ritchie
Faber and Faber, London, 1960

A Stroke in the Family by Valerie Eaton
Griffith Penguin Books, England, 1970

These two books are essential for anyone really interested in the medical model, the problems faced by intelligent patients when afflicted by illnesses which damage their capacity to communicate, and the struggle involved for them and their families in overcoming a condition which is accompanied by unequivocal brain damage.

Douglas Ritchie's book, subtitled **A Diary of Recovery**, is an account of a stroke from the inside, while Valerie Eaton Griffith describes a method she and others have evolved for furthering rehabilitation in the home and giving as two instances of this the cases of Patricia Neal, the famous actress, and Alan Moorehead, the well-known writer. Both books should, in my opinion, be read together, since one gains much more from doing this than either of them singly; yet even singly, they are remarkable and valuable works.

Ritchie's book is not quite so valuable to the specialist like myself whose particular interest lies in the **experience** of those suffering from various illnesses as was the work entitled **The Third Killer**, written by my old and lamented friend, the late Guy Wint (Chatto Windus, London, 1965). It would, I think, be best of all to read the three books together. Douglas Ritchie's work is shorter, less complex, and less philosophical than Wint's fine book, but this may make it of more immediate practical interest for those who deal with this condition, the families of patients, and particularly patients themselves. I would have thought that both books should be required reading for all those involved in these tragic illnesses, whether as patients, members of families, or of that large and various body of people needed for successful treatment.

Ritchie's book is made even more interesting by a brief foreword from Dame Barbara Wootton, describing his condition some 10 years after the stroke. At this time she sees him as having "developed a serenity and capacity for untroubled enjoyment that were never visible before." She then adds (page 13):

"Ten years ago when I visited him in a local nursing home and he had lost the faculty of speech, we used to play a sort of 20 questions game in a desperate effort to find out what he

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wanted to say. Today Douglas can conduct a conversation on any subject he or others may choose. True, he himself judges that his understanding does not reach more than 80 or 90 percent of normal, but whose wits are as quick at 60 as they were at 50? Sometimes also he is stuck for a word and a talk with Douglas proceeds rather more slowly than with most people, but this must be much more of an annoyance to him than to anybody else, especially as communication was his professional business."

Dame Barbara emphasizes that:

"The speechless, almost totally paralyzed man of ten years ago has exhibited himself to and addressed large medical conferences at home and abroad, has visited six European Countries and has lived at home by himself during his wife's illness, stoking the boiler, making omelets and all the rest of it."

She goes on:

"In time of trouble, old friends, some of them anyway, can be relied upon to remain faithful but new ones are not so easy to come by. Yet to my knowledge, Douglas, since his illness, has made a whole network of new friendships, which are as rewarding to the other parties as to himself. This, perhaps, is the greatest tribute of all."

Dame Barbara's comments must be taken in the context of his own words (page 25):

"I could not speak, my right shoulder, arm and hand and right leg and foot were dead."

This was the result of a severe stroke that occurred on the seventh of May, 1955, at about 6:30 p.m. It appears that he remembers very little until the end of the next week. But in addition to the symptoms already described, he found:

"I could not read properly, I could read half the caption, but the other half dissolved into vague lines. The caption was about three inches long and I read about an inch and a half and all the rest was meaningless lines."

He could read, but he could understand very little of the sense. At this time, he did not seem particularly worried. He says:

"It seems odd that I did not take a tragic view of my situation, but I realize that I insulated my mind against my physical

condition."

After about a month he was able to read some novels, but not others. Complex, allusive reading seemed very difficult, but simpler and straightforward writers could be assimilated. He notes:

"I had only to read a couple of pages when I knew it to be unreadable as far as I was concerned. Was it the style in which the book was written, was it the straightforward manner compared with the allusive complex manner or was it the things of the mind rather than the description of action that was the point, or was it simply the grammar, the short sentences that were all my brain could accommodate?"

Much the same things seem to obtain with some patients with schizophrenia, and there seems scope for an interesting inquiry from well-educated patients to find whether their reading interests have been substantially altered by their illness.

It was about this time that he had trouble with a kindly effusive middle-aged nurse, who made the mistake of talking to him in baby talk, supposing that because he couldn't speak this simpler talk would be helpful. If he didn't like a particular dessert, she would say: " 'Naughty boy, he must finish his tapioca, it's good for him.' Once she even tried to make me eat some custard, holding the spoon. My sickly smile refused to come on my face on this occasion and she said 'temper, temper.'"

His wife, who seems to be an extremely perceptive lady, spotted what was wrong and asserted his adult status to the nurse, thus cheering him up. It was, interestingly enough, the laughter which proved to be quite uncontrollable after his wife had asserted his status that convinced him that he had a serious illness (page 31):

"My paralysis and my inability to speak had not touched me. In a little while I would recover from these disabilities but the loss of control of myself seemed to be a matter of the brain. Laughing was all very well, and relief of it after the passion of rage, which the innocent nurse had conjured up, was quite understandable, but this laughter was sobbing and uncontrollable. However, my control was soon on again and I told myself it was nothing."

These outbursts of rage recurred, and he describes how it would sometimes take him as much as two hours to recover his temper. Looking back at the nursing home, he feels he was an impatient patient, and that being unable to speak built up tension which from time to time erupted.

Just about the sixth week he began to realize that his memory was very poor. He could not remember moving his bowels during this time and began to wonder, almost seriously, yet half in joke, whether he was being given a pill which would make bowel movement unnecessary. He says of this notion (page 33):

"What awful nonsense this was. This meant either I had been suffering from prolonged constipation, or I had no memory at all. I reluctantly chose the latter explanation."

It seems possible that he could have been assisted to come to this conclusion somewhat earlier by judicious, repeated explanation, such as the tape recorder permits.

After a month in the hospital, the fog which had clouded his brain began to clear and he pressed his wife to tell him again what was the matter with him. He writes (page 36):

"My wife had a difficult task. She had to skate her way between my conviction that there was not much the matter with me and the doctor's conviction that during the first week or fortnight there had been only a slender chance that I should pull through, and now there was uncertainty about the future but it looked like being a long hard job. But as I said before I had become insulated. I heeded only the most obviously optimistic things that were said to me and for the rest I did not hear them or came to the conclusion that they were wrong. If I had allowed myself to be given a glimpse of the truth, I believe I would have gone out of my mind. I let myself down gently until some two years later I reached the floor of the truth or at any rate the floor of my truth."

Gradually he began to recognize how serious his condition was. He observes that at this stage (page 38):

"But behind all this, I felt guilty. I do not know why I felt guilty, but something told me that I was. The illness had been brought on by

something. There had been a certain slackness about my work. For instance, I had begun to linger over my luncheon for an hour and a half or more. A half-filled diary pleased me better than a full one. Sitting at my desk, I used to let my thoughts wander at will instead of vigorously driving them where they belonged. Then there was the drinking. A large gin and french just before luncheon and two or three before dinner. I needed it but it spoiled my concentration, it was much too expensive. Whatever it was, the illness must have been due I considered to all these things. The feeling of guilt remained and I thought that all the visitors who came to see me knew or suspected my guilt."

If guilt can play such a large part in an illness which very few people would deny was largely somatic, it is hardly surprising that it is present in illnesses like schizophrenia and the major depressions in which there is less certainty. The presence of guilt, then, should clearly not be taken as a sign that the illness itself is entirely or largely psychological.

His wife adapted the game of 20 questions to his needs. Thus on a basis of yes's and no's she was able to tell what he wanted most of the time. After six weeks he was beginning to get impatient to go home. He felt that the doctors were taking his condition a good deal too seriously and that he would easily learn to speak again. He notes (page 43):

"Having no idea how really ill I had been, I was critical of the doctors and particularly of their slowness. I shrugged my shoulders at my wife's praise of them and longed to be in London where things would be, to my mind, very different."

At this stage of his illness, what is so very striking is his lack of insight, of which he says (page 46):

"It seems absurd now that I look at it two years later, that I had so little idea what was the matter with me. It did not occur to me that paralysis might remain."

Since he was both a fisherman and a pianist, he felt:

"To remove my right hand meant to remove half of my life. I refused even to consider this."

Then he makes a profound observation,

which again has much bearing upon the treatment of other conditions with profound effects on the central nervous system (page 47):

"So the wide disparity between the doctors' realistic point of view and my own very unrealistic view was a profound one. Looking back on it now, it seems to me it would probably have been better if I had had a shock very early on and if I had spoken or at any rate understood the same language which the doctors talked. I should then have realized that my recovery was a thing for myself and only for myself, and instead of the physiotherapist doing a half hour's work every day and grumbling about her suggestion that I should do some work in the rest of the day, I should have taken a leading part and the therapist simply the guiding role. And as regards speech, I should have realized that all that talk about currents and switches was nonsense and I should have gotten a speech therapist to tell me that I was in the position of a baby who starts learning da and mama from scratch and with her guidance to get started. If I had got started then and there within those six and nine months, there was a chance, or so it seems to me, of a recovery or a part recovery. As it was I only stumbled across some of the facts about nine months later and it was nearly two years before I was in a thoroughly realistic frame of mind."

He is not sure whether this discovery might not have been too hard for him to bear. However, Valerie Eaton Griffith's book, **A Stroke in the Family**, strongly suggests that with a stroke as with any other serious illness, the doctor has a responsibility at some time or other to be thoroughly explicit, to place the patient in the sick role, and to make certain that he understands both his duties and his rights in that role. I can find no evidence that Ritchie's doctors ever did this, even though they were capable, intelligent, humane men who helped him greatly. It does not seem to have struck them that although this might have been initially painful for him, it would have almost undoubtedly speeded up his cooperation in the long process of slow recovery. By the end of August he was at home and able to read the newspaper, but he

found that (page 60):

"Murder, sex, burglary, scandal, all these were relatively easy, but strikes with rates of pay that sounded so difficult and negotiation with arbitration or not were so confused that I could not understand them. So were politics and foreign affairs and all the rest of the newspaper context, with never the whole story in it but the balance yesterday or the day before."

He gives some valuable hints about the problems of getting dressed, going to the lavatory, shaving, etc.

Again (page 62) he emphasizes how little he understood his position:

"Thinking this over two years later, I came to the conclusion that there was a quarrel between me and the doctors. I do not know why this was so, but I was convinced that the responsibility for getting me well again was the doctors' and not mine. Perhaps it was due to the doctors' failure to tell me what precisely was the matter with me and add that I must create the conditions for recovery and that nobody else could. Or perhaps the doctors did explain to me and it was due to my own unconscious lack of attention that left me saying that who's ever responsibility it was, it was not mine."

In brief, the doctors had not inducted him into the sick role properly, had not defined his rights and his duties so that he was still in the role of the irresponsible patient.

His speech was so defective that once when a black rage filled him, he was able to pour out the following expletives at his physiotherapist:

"'F—king doctors, I—don't—know—what—the—f—king—doctors do, f—king—well—wait—wait—wait!' I gazed at him in utter astonishment, he gazed at me, then he started to laugh and I started too. Swear words were not familiar to me. I used an occasional bloody and bastard in the office, but this was the only way I hardly ever used bad language."

Swearing is, incidentally, a well-known symptom of his illness.

Seven months after his stroke, his morale was low. He didn't refer to it as a stroke, even to himself, because he did not know it as such. He couldn't remember its longer name and distrusted the doctors who he thought didn't know the cause or the cure. He was playing

very little part in fighting his illness. Two weeks after this he went to the Medical Rehabilitation Centre and began with speech therapy. He was still hoping for some "switch" which would magically cure him. He writes (page 79):

"I did not then know, and I wasted time in bursts of ill nature, in furious rages in thoughts of 'switches' and ideas of what was really the matter with me, when the doctors and therapists ought to have explained and answered the silence, which was not my fault."

He gives an excellent account of his experience at the Medical Rehabilitation Centre. On his first day there the occupational therapist, seeing he couldn't do up his shoes, showed him a better way of how to do this (page 90):

"I was much impressed by this, and the therapist took my shoes, and taking the laces out put them in a new way. I put them on again with ease."

This simple direct action seems to have been very helpful to him. In addition to direct action, he was given simple, direct explanations about the effect of working his muscles on his brain cells. These may not have been accurate or scholarly, but they encouraged him and they worked. He was at least as badly off as the worst schizophrenic in terms of speech, and regarding mobility, he was probably worse off. He needed an explanation which would encourage him to persevere and keep going on the exercises. For the first time he understood that his brain disorder was the direct cause of the paralysis. It had taken him almost 10 months to do this, which shows, I think, that the development of insight has little to do with the "functional" nature of illness and a great deal to do with the kind of explanation given and the way it is given and the capacity of the patient for understanding that information.

At the end of a year, when he had been at the Centre about three months, he was very pessimistic because of what he felt was a slow rate of improvement. Since he had been given no idea as to what rate he might reasonably expect, his estimate had very little bearing on

reality, and his discouragement reflects back on his not having yet fully acquired the sick role with its many advantages. About this time he heard from a friend of his, Clifton Utley, who had had a brain embolism about two years before. Utley's condition was very similar, but unlike Ritchie, he was very clearly unequivocally in the sick role. For the past three years he had been working with a doctor who had a special interest in strokes and his letter impressed Ritchie (page 99):

"I read Clif's letters a dozen times. I found them difficult. He evidently knew something about medicine or he had learned something about it since his illness. I knew nothing and still had to have 'stroke' and 'thrombosis' and 'spasm' and 'aphasia' translated for me. If I was still well, the words would have no doubt meant something to me, even if the meaning was not precise or accurate. But I had had the stroke and it was not surprising that my unconscious mind would not let my conscious mind remember such dirty words or forgot them just as quickly."

One difference that shows up again is that whereas his friend, Clif, was very much in the role of responsible patient, Ritchie, after a year, had still not reached that point. He had acquired little, or nothing of the medical jargon and seemed to be full of expectations that the doctors would perform some magic without his having to do anything in particular. He was disappointed that Clif's doctor did not seem to be able to offer any advice about his special method. This gentleman explained his position in these terms (page 105):

"The choice is to get this out tomorrow and have it discredited by the profession and forgotten about for fifty years or to prove every bit of it, even if it should take five years, and then submit it to the profession as a whole as something that is so well proven in theoretical physics {really biophysics} that it insists on acceptance. I know this seems like over-conservatism to you, thinking about all the patients like yourself who need treatment, but I am afraid that the patients who won't get treated in the immediate future must be regarded as casualties of the medical profession."

It appears that, however successful a

rehabilitates he may have been, he was profoundly ignorant of his own colleagues and very unclear about the nature of medical proof. However, one effect it had upon Ritchie was to persuade him that (page 105):

"This was the moment of truth . . . but this letter had the cold stamp of truth or the nearest thing to truth ever since the stroke had bitten off half my brain. Strange to say that it was relief more than ending of hope which pervaded my mind. Confusion and conflict of trying to make up my mind made me more ill than before. Now it looks direct. I'll go back to the Centre and if it looks to me as though there is any improvement, I'll stay. If it looks as if there is none, I'll get into the country."

When he got back to the Centre, he was lucky enough to meet another patient called Maklev who, he tells us, was a good deal more extroverted than he was. Maklev undoubtedly helped him to keep going. As Ritchie said (page 110): *"He was convinced that everything was possible until it was proved impossible. I was convinced that everything was difficult."*

But Maklev's example gave him the beginnings of hope which were later to prove very important in his reablement. Ritchie ascribes this to the fact that:

"Maklev was an extrovert (Clifton Utley was one too) whereas I was an introvert. I was conceited and humble at the same time. I liked to appear to be very important and yet I went pale at the suggestion that I should make a speech."

In stroke, as in any other illness, the basic personality is extremely important and has to be taken into account. Some personalities, like Maklev, are well adapted to getting better, and some like Ritchie are less well adapted. This should surely be taken into account in planning how to induct different patients into the sick role and how to insure that they become responsible rather than remaining feckless and irresponsible as Ritchie himself was for many months.

From this point on he begins to recognize that his own activities are going to play a much larger part in his recovery than he had previously supposed. He writes (page 114):

"Gradually I had come to two things—a slower mental tempo [which meant that I no longer thought at the pace which I did when I was well] and a faster physical tempo (which meant that I no longer lived at the pace that I did when I was first ill)."

At about this time, too, he decided to write the story of his illness, and this seems to have played a considerable part in his recovery. He also met Dr. O'Malley, the head of the Centre for Rehabilitation, who lent him Stanley Cobb's book, **The Borderlands of Psychiatry**, and it was this that started him on the road to becoming a fully responsible patient. He now began to learn about his symptoms and what they meant in terms of the illness which had afflicted him. After discussing the effect of Stanley Cobb's book on him, he writes (page 127):

"There is a mystery about books on illness. Many doctors refuse to let their patients read them. They say that the more ignorant among them are bewildered by the medical terms and feel that they are worse than is the case. I feel there is something in this but very often the doctors are rationalizing and refuse to give information for the unconscious reason that they are magical, or in the modern style scientific power will pass away with a patient's knowledge. But knowledge is nearly always better than ignorance for anyone, for patients as for doctors. The known, however bad it is, is nearly always better than the unknown. The patient, knowing what is the matter with himself, can help the doctor with his symptoms. He can keep a cool head instead of a mind nearly panic stricken with the unknown. He calls on the doctor less frequently and he is far less prone instead of more inclined to hypochondria."

"By reading these books, I at any rate was immensely helped. I was not only given things to do, but this is the much the more important thing for me, the reason for giving me things to do was apparent. Now, I did not write in my diary nightly out of respect for my therapist but because I knew it was the only way to get writing back to normal."

If this is so important in aphasia, it is certainly just as important in schizophrenia and exactly the same arguments are produced by doctors. Just how any

patient is supposed to become responsible without information and without the doctor encouraging him or her to become well informed has for many years been to me one of the greatest mysteries of medicine.

On September 2, almost 18 months after his illness, he writes:

"Last Friday evening I listened while I talked. It is the first time I have done so since I had the stroke, for it is the first time I have been consciously aware of my doing so. Before that I was talking but not listening. I was aware of the fact that I was talking but the listening was not conscious, but since last Friday, listening has been part of my talking."

In other words, he is now using a self-monitoring system.

It may well be that some schizophrenics lose this capacity or pay less attention to it and so tend to be less comprehensible than they would be if they listened while they talked.

It was sometime after this that he went to see a Dr. Harley, a psychiatrist. This is an excellent example of psychotherapy being used within the medical model. He feels that Dr. Harley gradually brought to his attention the fact that many anxieties had crystallized around his stroke, especially over the changed family relations brought about by his serious illness. What Dr. Harley seems to have done is to have shown him serious illnesses are accompanied by a great deal of anxiety, which lights up current psychological problems and often brings older ones to the fore again. This common sense psychiatry worked very well in a serious neurological illness.

At the end of his book he sums up his experiences and, in spite of a great deal of grumbling to be found in his diary at the time, looking back he feels that he was on the whole very well treated. The Medical Rehabilitation Centre rightly receives this commendation:

"It is indeed a remarkable institution. It offers a unique opportunity to the disabled with its up-to-date daily program of treatment from 9:15 a.m. to 4:45 p.m., remedial exercises, physiotherapy, speech and occupational therapy, all coordinated and

carried on under one roof within the National Health Service. My recovery, such as it is, was found during 18 months at that Centre."

I wonder how many of our patients here and in psychiatric units of all kinds have such a program aimed at the needs of the patients. Douglas Ritchie put in what amounted to a full working day aimed at helping himself to recover. It seems to me that in psychiatry we have very few equivalents of remedial exercises, physiotherapy, speech, and occupational therapy. And those which we have are not deliberately aimed at speeding recovery, but are diffused by our various, often conflicting theories. Yet our patients, too, have disturbances at the higher level of the brain functioning which, while not identical with those found in strokes, have a good deal in common.

At the very end of the first edition of this book he wrote:

"A publisher's reader on reading the manuscript of this book said, 'He had a pretty poor time of it, but my heart goes out to his wife, she deserves the George Cross.' "

How true, yet how seldom do we give the wives or mothers of our patients the credit which they deserve and which would put new heart in them to continue the battle against illness.

The last 20 pages of the book are a supplement written in 1965 in which he points out that although his right arm and hand are useless, his speaking, writing, and understanding are all still improving. He has learned to monitor himself so that he knows when he is becoming tired and does not push himself too much, something that many of our schizophrenic patients have also learned to do. He says (page 167):

"If I am tired and lacking in concentration, I fail to distinguish what is said to me. Either I notice the words but think nothing of them or I fail to notice the words and there is just noise."

He even gives a simple quantitative test to show how much he has improved (page 167):

"In counting, there is a good way summing up concentration in executive aphasia. An ordinary man or woman in health I estimate can count up to several hundred without

making a mistake. In 1957 I could count up to 13 or 14, then I said 11 or 17 or something idiotic, but now I can count up to 23 or 24 or maybe there's concentration enough for me to take up to 26 or 27. It does not matter, anyway, my wife will look after 28 and 29."

In 1963 after his book was translated into Norwegian, he addressed a gathering of 650 people and after this exertion felt drained. His concentration fell away, his speech was reduced, and depression set in. However, when he got back to England, he realized how much he had done and felt a great deal more cheerful. At the end of the book he says (page 174):

"When the stroke struck me at the age of fifty, my life became incomprehensible, nobody would tell me—or I would not let them tell what was the matter with me, and when they did, or I would let them, my life was one of blank despair. Now at the age of 60, I am healthy and independent [with the exception of my tennis elbow] and in recent years, my life has been full of surprises, full of excitement and full of satisfaction."

He has written an admirable book and all those interested in the rehabilitation of schizophrenic patients should read and learn from it. As I have noted the conditions are not the same, but there are many resemblances.

Having read Ritchie, then one should turn to Valerie Eaton Griffith's **A Stroke In The Family**. Here are set all kinds of techniques for speeding recovery and teaching those who have had strokes to become more independent and play a greater part in getting well. It also gives an exact description of how one can get a genuine community involvement in rehabilitation by which relatively untrained people can make an enormous difference to the patient, providing them with services which would be impossible for any except the very richest. Even the richest would not get the feeling that their friends were doing this for them for nothing and so be given a special incentive to do their very best to overcome their misfortune. This, too, can surely be applied to schizophrenia.

Strangely enough, in Bryce Hospital in the mid-1960's due to the enterprise of our Psychology Department, which then included Doctors Dorman, Paul, and Reynolds (the last two are still with us), something very similar was being done for schizophrenics.

Unfortunately, in the catastrophes which overcame the hospital at that time, these remarkable innovative programs came to an end. We must see that they are salvaged, and perhaps with some of the new knowledge which we now have about the experiential world of schizophrenics they can be made even better than they were. For unlike a stroke, in most cases of schizophrenia there is no permanent damage and we know that many patients recover and become completely well. Unfortunately, as with Douglas Ritchie at the beginning, patients are hardly ever told about those who get well. Indeed, until Ritchie's book was written, it seems that sufferers from strokes were most unlikely to get encouraging information written by someone who had recovered.

All those concerned with treating schizophrenia, using whatever methods are available, should pay the greatest attention to books such as Ritchie's and by learning from them provide appropriate services for our schizophrenic patients. Perhaps most important of all is that books of this kind show that one sufferer from an illness can help others, sometimes thousands of others. It is our duty to make it easy for those who have been ill to let other patients know and so give them the benefit of their recovery.

It must surely be our duty to make it not only possible but easy for patients who have surmounted grave illnesses like stroke and schizophrenia to let other sufferers know about their success in tribulation. Those who are in the depths of despair can be greatly benefited from learning about these gallant battles of recovery. Accounts such as those of Douglas Ritchie show that by denying patients the sick role, or not making absolutely certain that the role of responsible patient has been acquired, recovery may be delayed or even perhaps reduced. No one would wittingly deprive a sick person of the chance of getting well, but who knows how often this occurs unwittingly?