

Dr. Osmond's Memos

A BRAVE RESPONSE TO A PERCEPTUAL DISASTER

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Journey into Silence

Jack Ashley

The Bodley Head, London, 1973

This book is worth reading for two entirely different reasons: it is a very good political autobiography which tells with admirable brevity, wit, and modesty the story of how a young shop steward in the north of England became a graduate of Cambridge University, BBC television producer, and Member of Parliament, and was on the road to acquiring a minor position in the Labour Government of 1966. Interesting as this may be and well written as the book undoubtedly is, this alone would hardly commend it to the readers of this **Journal** or lead me to recommend it to all those who are interested in schizophrenia, particularly those concerned with forming such groups as Schizophrenics Anonymous. I would also urge that it have a place in every medical library. The reason for this eccentric advice will be found in the title of the book, **Journey into Silence**, for just when Mr. Ashley seemed to have succeeded beyond his greatest hopes and was beginning to establish himself in Parliament, he became totally deaf. It is his account of this tragic experience and the way in which he has surmounted it which should be of consuming interest to all those concerned with perceptual disorders.

His misfortune stemmed from an attempt to correct a minor hearing deficiency which was causing him some slight difficulty in the large rooms and halls of Parliament. Unfortunately, the result of this minor operation was to render him totally deaf, and his hearing has never returned. About one-third of this book describes this catastrophe and his courageous response to it. The book is full of remarkable illustrations of how a courageous and intelligent man, blessed with a remarkably loyal and perceptive wife and a sympathetic family, deals with an appalling misfortune.

At the very beginning of the book he gives a good illustration of how easy it is to misunderstand the behavior of a perceptually-disordered person. "I was still unable to hear speech even with a hearing

aid, but by banging a spoon on the table or a piece of china, I could hear a vague blur of sound. I did this constantly, checking my hearing in the only way I could until the nurses asked Pauline if there was anything wrong with me. I was making such a din, they probably thought the deafness had affected my mind" (page 12). Such misunderstandings occur repeatedly in all illnesses with perceptual anomalies and are, of course, seen frequently in schizophrenia.

At the very beginning of his illness, in addition to the loss of hearing, with the enormous changes which this entailed, he

developed the condition known as tinnitus which he describes in this way, "Soon after entering the hospital, I heard the Liverpool trams clanking and roaring outside, but—remarkably enough—their screeching and groaning sounds did not vary with the changes recorded on the technician's equipment. The first time I was allowed out of bed, I went to the window and looked out into the street. To my astonishment, there were no trams or tramlines. The clanking and roaring I could 'hear' were noises within my head, known in the medical world as tinnitus. Head noises are a profoundly distressing byproduct of some forms of deafness and they are incurable; my experience was the first dose of daily suffering which any victim endures throughout his life. Doctors and consultants are helpless so I was faced with the prospect of living in the worst of both worlds. Deprived of any meaningful sound, yet denied the tranquillity which others imagine to be one of the tiny consolations of total deafness."

Ashley's perceptual illness then is not merely the negative one of the removal of sound, but the positive one of the intrusion of unpleasant and uncontrollable sounds which, fortunately however, he locates within himself and does not try to explain upon some quite reasonable but wholly mistaken view that they arise from outside influences.

To make matters worse, this time his wife unfortunately breaks her arm, and he makes this interesting point, "Gradually we began to notice the contrast in the attitude of the nurses to each of us; they were far more concerned about Pauline's injury than about my deafness. One disability was visible, the other was not, and this affected their attitude. We were able to laugh about this at the time, but it was a foretaste of the future when some people were to treat me with mere condescension if I failed to understand what they said."

At about this time, his doctor explained to him about the possibilities of lip reading. This, Ashley writes, "Of course it was an overstatement because mastering lip reading takes years and, even then, it is a poor substitute for hearing. Yet without his encouragement, I would have despaired in the next few months. He made me feel that there was a

mountain to be climbed and I resolved to climb it. Otherwise, I might never have coped with what was to follow."

This is an excellent example of a doctor giving hope that best of medicine so frequently neglected, particularly in psychiatric illnesses. Ashley describes the great depression he felt on his return home, for his deafness made it impossible for him to take part in the social life even of his family. He writes, "I was astounded to see them sharing a car with me, yet having a conversation from which I was totally excluded. The hospital environment had insulated me against reality which now had to be faced."

He had not really been prepared for this while in hospital, and thus shows an unnecessary misfortune which affects many schizophrenic patients. Luckily for him, with an illness that is relatively easily understood and a devoted and courageous family, he did not become totally isolated, as the book shows. Indeed, within a short time, he was hard at work learning lip reading of which he says, "Lip reading is an immensely difficult, grossly inadequate substitute for hearing; the miracle is that with all its difficulties, it still works at all."

After some months he returns to Parliament and describes himself on the terrace after his first visit to the chamber, "When he left me I sat alone on the terrace, watching the Thames. It looked bleak and cold. It was early evening and, although I did not expect the river to be busy, it seemed exceptionally still and silent. I thought I had known despair, but now I felt a chill and deeper sadness, as if part of me was dead. After a while I went back to the chamber where the debate was continuing but, as speakers made their points, there was for me total and unbelievable silence. Each member on his feet appeared to be miming. My last support, that vague buzz of sound which had come to mean so much, **had** vanished—perhaps obliterated by the last

desperate use of the hearing aid. At that moment, I felt in my heart that I had begun a life of tomb-like silence. I took a final look around the chamber before leaving for home and my family, and to prepare my resignation from the House of Commons." He was now totally deaf.

He describes this world of deafness extremely well. He notes that most of his friends believed that he was simply hard of hearing and had little grasp of what total deafness would mean. This book, I think, will make it much easier, for those of us who wish to understand some of the consequences of perceptual illness, to grasp the misfortunes of this particular kind of burden.

While making up his mind, he was lucky enough to meet the distinguished sociologist, Prof. Peter Townsend, who urged him to remain in Parliament, to help disabled people, but, in addition to this, to be a benefit to Parliament by being disabled himself in their midst. He reminded him that Sir Ian Fraser had served for years as a blind Member of Parliament and had done much for the blind by his splendid example.

Oddly enough, Ashley never seems to have met Sir Ian or to have discussed the consequences of these quite different perceptual anomalies with him. This omission impresses me because it shows how difficult it is when one is suffering from one kind of perceptual problem to relate it to another kind; yet, by doing so, much can often be learned about both. He describes his first visit to the House of Commons after his deafness, "After a few moments, I tried to lip-read. I had not expected to be able to understand much, but the reality was a chilling experience. I understood very little of what was said and, to add to my discomfort, I had no idea where to look. By the time I had swivelled around to locate a speaker, he would be halfway through the question. A brief one would be finished before I could start to make any sense of it. As this did not seem like the chamber where I had vigorously interrupted other speakers and impatiently awaited my turn to speak, it was transformed into a mysterious, menacing arena where I could be trapped into misunderstanding the arguments and passion which

swiftly ebbed and flowed. It would be all too easy to make a fool of myself. Somehow I had to make sense out of this silence and, as I sat there, I reflected on the daunting prospect."

This time, he noticed for the first time the shifting patterns of light in the chamber which, when his hearing had been normal, had never struck him. This passage only illustrates very clearly how changes in one sense modality produce a variety of changes in others. But his great difficulty was in making social contacts. He says, (page 149), "During the weeks and months that followed, I was gradually compelled to face the realities of my situation. Making contact with other members was a remarkable experience. Whenever I attempted a conversation with them, there was always an invisible but impenetrable barrier between us. Invariably, conversation began affably, but ended in confusion or sometimes embarrassment. If they could not make themselves understood, there was little left to do but jot down a note."

This had, of course, an affect upon a good many of his acquaintances in the House of Commons. Easygoing conversation was completely disrupted, but he had one advantage over many of those suffering from schizophrenia. He knew why and, although he found it most unpleasant, he says, "Human nature being what it is, my relationship with many members was inevitably eroded by deafness." Nevertheless, a number of his friends stood by him. Not only did he have problems with lip reading, for he wasn't very expert at this time, but, in addition to this, he had great difficulty in adjusting his voice since, of course, he couldn't hear it, and he describes this in these terms, "Another problem was my voice. As I was totally deaf to sound of any kind I was unable to hear my own voice and it was sometimes difficult to control the volume. The tendency was to shout—perhaps the subconscious effort to hear what I was saying and, when I did so, the modulation and pitch could be adversely

affected, but lowering my voice sometimes made it inaudible. When I spoke I did so from memory, and the only guidance was the delicate vibrations of my throat muscles. At that time, this was inadequate, and my clearest indication of shouting occurred when people beyond my circle looked across."

At this time, he attended a meeting of disabled people in Trafalgar Square and derived great comfort, help, and support from this; he writes, "The plight and courage of these people, so totally dependent on others, moved me and gave me a sense of perspective. I had been feeling anxious about my own performance in the House of Commons a day or two later, but this example showed me the need to forget my own problems and to state an effective and persuasive case on their behalf." He arranged with a colleague to give him signals to avoid speaking too loudly or too low. The speech was a great success. The Prime Minister congratulated him, and he says of that day, "It was a significant day and, in its own way, a landmark; to my knowledge it was the first speech by a totally deaf man in any legislature in the world. For me it was also a happy day. I was in the company of those who understood and helped me to return. I noticed the Thames no longer looked bleak and cold, but seemed to reflect a new sparkle in the air." In this way, he gained appropriate self-esteem for having done something that nobody had done before. In addition to this, he received the support and encouragement of his friends and colleagues.

He notes with great skill that his deafness changed social relationships. One of his friends clearly believed that, because Ashley was deaf, he had now become more stupid and showed this. However, as he writes, "His new dogmatism was no more than a bubble of superiority, a feeling that a man short of one sense must be short of sense in general; it was amusing, but it was essential to prick the bubble. Having done this, I could again enjoy his genuinely pleasant companionship." Ashley's capacity for seeing the other person's point of view, yet not allowing himself to be crushed by the supposed changes in status, must have done much to prevent

him from becoming resentful and bitter. It is easy for those with illnesses of any kind, particularly perceptual illnesses, to fall into the paranoid trap, and Ashley's book is an excellent guide for avoiding this misfortune, which simply compounds the illness.

He gives many examples of how friends helped him and other examples of how things went wrong. For one who depended on lip reading, for instance, a friend who did not move his lips when talking proved an insuperable barrier. Because of this episode, "Although we provisionally arranged another lunch, I have never heard from him since and, of course, I don't blame him. Such is the threat of deafness to relationships, even when really genuine friends are concerned, if I am unable to lip-read them adequately."

He has a splendid story about his youngest daughter, Caroline, who would tease him by talking complete gobbledy-gook and would then be greatly amused at his attempts to lip read, which caused a great deal of fun in the family. When he tries to bluff her, after failing to lip read her, and pretending to understand, she asks him, "What did I say?" and this has been helpful to him in avoiding trying to bluff. He found conversations with several people particularly difficult.

He finds out, too, that there are all kinds of traps for those suffering from perceptual illnesses, which occur in the most unexpected places. Poor lighting, for instance, makes lip reading almost impossible. He says of the deaf, and this applies to all people with disabilities, particularly perceptual disabilities, "Most people are more concerned about the difficulties deafness creates for them rather than difficulties confronting the deaf." One of his colleagues said to him, "It was very difficult for us, because we were more embarrassed than you were." How little he knew, and how revealing his comment! Another friend was much more helpful; his reaction was, "Don't apologize

—it is far more difficult for you to lip-read than it is for me to repeat things." His comment showed an uncommon degree of comprehension.

In Chapter 16, he discusses the world of the deaf. He discovered, for instance, that the charitable donations to the blind amount to some two million pounds a year, while those for the deaf, only one-hundredth of this—twenty thousand. Organizations for the blind are understandably not very keen to help the deaf. He observes, "No comedian would ever win a cheap laugh about the misfortunes of a blind man, but the deaf are a source of endless amusement."

Equating the deaf with the daft is not confined to music halls; the public readily assumes that one malady is synonymous with another. Thus, they strike at people already stricken. He adds, "The first public statement I made after my loss of hearing had been that I hoped to come to terms with the problems and reduce deafness to a minor irritation. This was a brave but foolhardy comment which annoyed some people with long experience of the disability. They knew how profound and far-reaching its effects can be and rightly felt that I had minimized them. Deafness is the most misunderstood disability of all and, in those days, I misunderstood it, too."

Here, of course, he is not quite correct. There are other perceptual disorders, particularly schizophrenia, which are even more misunderstood than deafness, but, nevertheless, the point he makes is an admirable one. Unless those who suffer from these illnesses, as he does, make these problems explicit, no one else is going to, because they are in no position to do so. When he addressed the Otolological Section of the Royal Society of Medicine in Wimpole Street, he was much disappointed, as he writes, "I was dismayed at the lack of interest in the terrible problem of tinnitus. Their knowledge of it was slight. One surgeon asked my advice on what he should tell patients who suffer from tinnitus, but he was supposed to be the consultant." One reason at least why otologists have been neglectful of the distresses produced by these paradoxical perceptual changes in deafness, that is, by deafness being accompanied by strange noises, is

that there have been so few books like those of Ashley's and so little pressure and encouragement to work upon this mysterious problem.

The inner experience of the deaf is even more difficult for people to imagine than that of the blind. And even here, people can be remarkably unimaginative. Legislators who understand this medical lack of understanding are needed to push the case for adequate and sustained study of the misfortunes which afflict all those with perceptual disorders. One can only hope that this energetic and able man, who has done so much to conquer his own misfortune and shown such courage and resolve in doing so, will be able to extend his range in the future so that he will link up his interests with those of another member of his own party, Mr. Christopher Mayhew, an old friend of mine, who has for years been devoted to the problems of mental illness. It seems at least possible that neither of these members of Parliament, both greatly interested in helping those with disabilities, have recognized that, improbable as it may seem, deafness with its loss of perceptions, combined with an excess of strange and distressing head noises, and schizophrenia, with its distorted and strange perceptions, have produced rather similar problems.

Common sense suggests that they would not do so, but common sense is frequently mistaken. It is, for instance, particularly interesting that Ashley, who has been a BBC producer and is clearly a man of great energy and devotion as far as the disabled are concerned, and whose courage and resolve must be of enormous help to them, does not seem to have consulted with Sir Ian Fraser, the blind MP. Even if he has done so, he did not consider it relevant to his particular book, for common sense says that deafness is different from blindness. But deafness and blindness resemble each other in that they are

perceptual disorders, as indeed are most grave disabilities, for, at the very least, they change our perception of ourselves and the way in which we are perceived by others. Frequently they do much more than that. Deafness and blindness are conditions in which some aspects of perception are removed. In schizophrenia, all aspects of perception may be distorted, uncomfortably enhanced, and sometimes much reduced with all kinds of social misfortunes accompanying this.

I look forward to the time when admirable books such as this will be seized upon quickly by those with schizophrenia, blindness, as well as those with deafness, and used to impress upon doctors, legislators, and others the need for a more imaginative and determined approach to the consequences of perceptual disorders in illnesses. As the late Guy Wint showed in his splendid book, **The Third Killer**, which tells of his stroke, his greatest misfortunes were occasioned by perceptual changes. Schizophrenics have written repeatedly on this topic. My own experience of going blind, then being recovered miraculously by surgery, indicated to me that both the loss of perceptions and their restoration produce all kinds of unexpected

consequences. The victim is quite unaware of these unless he or she has the good fortune to know what to look for and the kind of problems that may arise. This is a very helpful book, but I only hope that its writer will use his prestige and influence to see that adequate and sustained inquiries are made so that those who are smitten with total deafness or with any other perceptual illness receive the kind of information which they need so much and which, as he shows, in spite of the best intentions, they so often don't get.

I also hope that he will use his connections with the BBC and the mass media generally to urge upon them that it is their duty to present a more comprehensible, interesting, and sympathetic account of these grave and very frequent misfortunes. Any of us may be and many of us will be afflicted by some and possibly a variety of perceptual disorders. What we need is doctors, nurses, families, and friends who know how to help us in our grievous need. *Journey Into Silence* is an admirable guide book and I hope no readers of this journal will neglect to obtain it and to read it with the greatest care and attention.

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