A Letter to The Times

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Editors' Note

The Times (London), May 9, 1970, published the following letter concerning a young man's suffering with schizophrenia as described by his father.

The best, but not the safest way to become aware of the schizophrenic experience is to have the illness; the next best is to attend carefully to the spoken and written accounts of those who have suffered from it and the descriptions of their sufferings by their relatives or friends.

Books such as *The Witnesses* by Thomas Hennell, *In Search of Sanity* by Gregory Stephan or *Gone Is Shadows' Child* by Jessie Gray Foy are often more instructive than the psychiatric texts which frequently describe schizophrenia as if the authors had never listened to what the patients or their relatives say. In a way, this is true. It has been the custom among psychiatrists to preoccupy themselves very little with what patients actually say and to devote their energies to either explaining the structure of the patients' thoughts and feelings or the "true meaning" of the patients' utterances.

These interpretations dignified with the label psychodynamics have blossomed into an industry of explanation filling hundreds of volumes. As a result of this, nearly everyone who is in contact with a schizophrenic patient feels more obliged to explain what they are saying than to listen to what they say and to ponder its meaning.

The letter which we are reprinting here is the illness as seen by the father. Some notes on that letter by Dr. Humphry Osmond are appended.

Schizophrenia is a fragmentation or disintegration of the ego, that central "I" or "me" which we all take for granted, unaware of the delicate balance of the elements inside us. According to the severity of the attack, the effects may range from a mild disasso-ciation or personality to a total withdrawal from human contact. Virtually nothing is established about its aetiology or its genetic, environmental or other predisposing factors, so no means exist for either prevention or permanent cure. It may strike at any age or in any walk of life, but there is a distressingly high incidence among young adults, including those of beyond average intelligence.

The symptoms may shade into those of many other conditions so diagnosis can be difficult.

My son succumbed to an alleged "depression of adolescence" in his second year at Oxbridge, where he had gone with a major open scholarship. He began cutting lectures and tutorials, shutting himself off in his rooms, and avoiding his friends. It did not occur to the college authorities that this behaviour could be due to anything other than idleness. They neither sent him to a doctor nor told us, the parents, but first took away his scholarship-then as that had no effect, sent him down—with 24 hours notice to us. They admitted-afterwards—that suicide notes had been found.

A family suddenly faced with this situation has, in my experience, two problems and it is hard to say which is worst. The first is how best to cope with this strange, new member of the household whose moods alternate impossibly between sullen lying on his bed in the dark to wild fits of aggression, with social manners regressed to an almost animal level. The second problem is how to penetrate the obfuscating fog of hospital vagueness and evasiveness to obtain intelligible guidance on the first set of problems.

It is understandable that psychiatrists are chary of affixing a dreaded label too quickly, and in fact it was more than two years after a round of several hospitals and a disastrous second attempt at Oxbridge, before a positive diagnosis of schizophrenia was made in my son's case. But looking back, were those long months in which we could get no practical sense out of anybody really necessary?

On almost any specific point on which advice was desperately needed—should he be persuaded to get up, dress, keep himself clean, encouraged to work or study, or just be left alone, which course was best for him? We grew used to receiving from the doctors weary platitudes about showing "patience", or, from the hospital "welfare" side, surprised counterquestions—"Didn't you ask the doctor that?" Failures in coordination and communication seem to hang about the administrative management of schizophrenia almost like a grim parody of the condition itself.

A personal experience of this kind is inevitably subjectively coloured, but it has persuaded me to look into other cases with which I have no emotional link, and into the general question, and my conclusions are disturbing, particularly about the community provision for the victims of the condition.

Some schizophrenics make a partial recovery. Some stay in hospital for keeps. But thousands more in Britain (the statistics

are unreliable) level off like my son at a low level of adaptation, physically fit and normal-looking to a casual outsider, but without application or anything that can be called will-power, and finding most inter-personal relations almost impossibly difficult. Drugs exist which palliate the grosser behavioural disturbances. They make life more tolerable for the sufferer and those around him, but it is hard to hit on a dosage which will not produce a somnolence as inhibiting to normal living as the excess emotion the drugs are designed to suppress or mask. Cases vary, but the very success of the drugs may only make it harder for the outside world to understand that behind the resulting apparent and outward normality the mental fragmentation is still there.

The community problem chronic schizophrenics present is that while not ill enough to be made the subject of a compulsory order, they are incapable of looking after themselves without special guidelines and supervision, notably of either finding a job or, still more, of keeping one. Our son spasmodically looks for the job or occupation which, with one part of his mind, he wants. If he gets it he either does not turn up or he leaves it the same day. He has less sense of money than a child of 10. And each failure with each successive employer, each inability to obtain references, answer letters, keep appointments, repay debts, make the chance of anything better progressively more remote.

MADDENING VAGARIES

Schizophrenics tend to leave behind them a trail of people who righteously, or despairingly, feel they have "done as much as we can" and it should be somebody else's turn. I have quite a collection of sympathetic letters "hoping your son's condition will soon improve" while regretfully saying "no" to some specific request.

Such reactions are all too intelligible, bearing in mind the maddening vagaries of schizophrenics and the difficulty of fitting them into any normal pattern of living. They excite none of the sympathy which surrounds other classes of the disabled. Even close relatives, let alone official bodies or employers, find it not easy always to choke back the feeling that there is something morally culpable about people apparently fit and rational who fling up work without excuse, and whose hands, as the years go by, increasingly close over any small gift of money with what looks like complacency but is in reality only a sad acceptance of their inadequacy.

As regards their ultimate disposal, if one must use the callous term, they present a problem which, it seems to me, the community and the authorities just are not facing. The priority matter is clearly rehabilitation wherever this is possible: a dual task of resocializing to enable them at least to scrape by in company with normal people, and simultaneously fitting them to do some simple job, possibly very much part-time, but at least permitting them to live independently, if only at a modest subsistence level. Central or local authority provision for retraining geared to the needs of schizophrenics (or for that matter, former mental patients in general) is virtually non-existent.

The Industrial Rehabilitation Units set up by the old Ministry of Labour are primarily intended for physically injured or handicapped manual workers. They are too few and scattered in view of travelling difficulties, but that apart, they concentrate on industrial retraining whereas many schizophrenics are only fit for routine clerical or similar work and are often so manually clumsy that to let them anywhere near lathes or power tools is inviting trouble. Worse still, the Industrial Rehabilitation Units naturally expect punctuality and the keeping of regular hours, both of them major hurdles to the average schizophrenic who after an initial failure seldom goes back.

To meet the resocializing part of the rehabilitation process a recent Act laid on local authorities the obligation to establish hostels to act as "halfway houses" for mental patients between their discharge from hospital and the hoped-for resumption by them of normal living. The aim, the provision of an interim sheltered environment, was admirable, but only a handful of local authorities have in fact done anything. And of those who have, some have interpreted their task in a grudging, obscurantist spirit.

The so-called halfway house set up by a wealthy county close to London is run on strict disciplinarian lines. New arrivals have it rubbed into them that their first duty is to get a job and get out. Use of the premises is forbidden during the day, almost as though intended to make the inmates feel rejected and walk the streets aimlessly, a favourite schizophrenic way of passing the time.

Pressure on schizophrenics to obtain occupation may be right, for their own sakes and to prevent deterioration, but hectoring is counter-productive and the ambience which brings out their best is more that of an oversized family than an institution. For this reason the most successful halfway houses are those set up

by such admirable voluntary bodies as the Richmond Fellowship whose staff must by now have as much experience of schizophrenic rehabilitation as anyone in the country. But there are tragically few of them.

When all is done a hard core will remain, possibly running well into five figures of the United Kingdom, who will never be capable of fending completely for themselves. No social provision exists for them, so their future is bleak. As parents die off and other relatives find it impossible to cope, the inevitable trend is for them to drift downwards to the welfare state's bottomest sump. A recent "Panorama" item gave a grim but accurate account of what is already happening to many; discharged from hospital to nobody and nowhere, feebly attempting casual work, neglecting their medication, failing even to collect their "public assistance" ; the will-less slide to the doss house or sleeping rough along with the meths drinkers and drug addicts, involvement with police and prison, or, if lucky, back to hospital and starting the process over again.

Mental hospitals or institutions for mental defectives are totally inappropriate for giving shelter to chronic schizophrenics, but where else can they go? What is wanted are small residential settlements where their simple basic needs, including protection from impossible stress, can be provided in a mutually supportive environment. Such homes would be far cheaper than a corresponding occupancy of places in mental hospitals with their high medical and other overheads and where any attempt at normal living, to which they pathetically cling, is impossible.

AVOIDING WASTE

Many of the necessary jobs could be done by the residents themselves ; schizophrenics will often work well enough in their own fashion if someone they like will tactfully "organize" them and is tolerant of their vagaries. There would also be scope for sympathetic local employers, not expecting too much, to give them a try. Such small communities would fill a gap in our social provision, avoid the friction and waste inherent in the present administrative neglect, and offer thousands in the hard core their best chance of happiness.

But the whole administrative setup for dealing with this category of the disabled needs pulling together. The mentally crippled can almost be relied on to hurl themselves through any safety net devised to catch the ordinary disabled but this should be fore-

seen at the planning stage. Unaided, they cannot be expected to cope with the bewildering maze of authorities which impinge upon their lives: out-patient departments, almoners, departments of employment and social security, inland revenue, hostels, local authorities, Industrial Rehabilitation Units, each with its demands for documents, replying to letters, giving precise answers to incomprehensible questions—and none appearing to be in touch with the others.

The ideal would be for some one authority to be given a coordinating role and designated as that to which schizophrenics can turn in all matters affecting them. If this involves registering them that too should be considered. The scandalous fragmentation of responsibility between local authorities and the hospital service—the one wanting schizophrenics off the rates even at the cost of their occupying expensive N.H.S. beds, the other responsible solely for the medical aspects and unconcerned with any comprehensive after-care—should be ended.

A unified national policy is needed.

It is sad that this article by an intelligent parent could be written in May, 1970. The writer's strenuous efforts to get usable information about his son's grave illness failed even though the illness is a frequent one and much is known about it. This young man's father would have been better informed had he read William Batties' book *Treatist On Madness* (1758) or John Conolly's *Croonian Lectures* given in 1849 at the Royal College of Physicians in London.

It is not, of course, true to say that virtually nothing is known about schizophrenia. A phone call to Dr. Eliott Slater at the Maudesley Hospital in London would have at least resolved these worries. What is true, and what this letter shows to be true in a valid and tragic way, is that what is known is hardly ever communicated either to the patient or to his family; but that is not quite the same thing.

In paragraph two, the onset of the illness is very well described. There must be hundreds of such cases. Oxford or Cambridge did not appear to expect any of their students to develop schizophrenia. Nobody kept a weather eye lifting to spot its occurrence. No attempt was made to catch it early. Indeed it sounds as if its presence was ignored so that an obviously ill boy was allowed to become iller and then was rejected with brutal suddenness. It was appalling and unjust that before removing his scholarship nobody asked why a boy who had done so well now was failing utterly.

However, when the ignorance shown by the university is set against the parents' ignorance, the astounding slowness and inefficiency of the hospitals in diagnosing his condition, it becomes evident that we are dealing with a general and not a particular fault. This must be remedied. It can only be done by organizations like the American and Canadian Schizophrenia Associations prepared to devote themselves single mindedly to the cause of this great illness.

It is doubtful whether this particular boy will ever recover completely now; not be-

cause he is incapable of recovery—he still has a fair chance, but about one third of his life has been squandered due to ignorance which should not exist in the late twentieth century. A nurse equipped with an HOD test could have gone a long way to diagnose his illness in the first few months at Oxbridge. At that time mega vitamins combined with tranquilizers, adequate explanation and an appropriate regimen would have prevented this catastrophe and converted it into a minor, though undoubtedly frightening episode. This cannot be done now because the young man has been disgraced and humiliated by the failure to diagnose and treat his illness rapidly. Putting Humpty Dumpty together again is far far harder than steadying him when he and the wall are just beginning to sway, lurch and shudder.

It is charitable, though hardly correct, to justify psychiatric unwillingness to diagnose schizophrenia simply on grounds of squeamishness. Apply this to other illnesses and one can see at once that it is absurd. One does not congratulate a doctor who fails to diagnose tuberculosis until one has coughed up a pint or two of blood. Neither is it good practice to avoid diagnosing cancer until one is sure that there are secondaries simply because it may seem unkind to tell the patient the truth. Indeed in these two illnesses failure to diagnose may result in a far more serious or even fatal outcome which could have been avoided by prompt action.

Public tolerance in this respect is harmful. An insistence upon early and accurate diagnosis is likely to result in better treatment and better care for the ill. One of the odder aspects of so-called preventive psychiatry has been that although much lip service has been paid to it, the necessary efforts for making prevention possible are little used. Prevention calls for accurate and early diagnosis as an essential first step, but very little interest has been shown in developing means for doing this.

Our failures are rationalized with the comfortable notion of "what could we do about it anyway even if we did diagnose earlier?" Our findings strongly suggest that much can be done now. However, even if nothing could be done, early and accurate diagnosis strongly encourages the search for better treatments. It is painful but necessary to ask oneself, how this correspondent's tragic son has felt about his decade of illness. From this account, after leaving school he obtained a major scholarship to a great university. There he developed a very mysterious illness which resulted in his first being degraded by losing his scholarship and then being thrown out precipitately; a cruel business.

Even after he was diagnosed as being ill, things didn't go much better. Ten years later his father, although greatly interested in this illness, remains very ignorant; there is no reason to suppose that the victim of it is any more knowledgeable. If his experience resembles that of many other young men whom I have seen, he has never had the simplest explanation given to him about his illness and neither have his parents. By all accounts, he is an extremely intelligent young man who would have been able to put such information to good use.

This lack of explanation aggravates the patient's feeling of helplessness and despair, while reducing the parents' ability either to understand or to help. From this account it seem that the rehabilitation arrangements available in England were not very suitable for this particular illness; not because those involved are unkind or neglectful, but because they too, are ignorant of the patient's experience and so more or less are incapable of planning a rehabilitation program which is designed to benefit patients suffering from this illness.

One has only to consider how difficult it would be to rehabilitate blind patients if

one was under the mistaken impression that they were deaf, or vice-versa. Because until very recently there have been no health associations devoting themselves solely to this illness, the mysterious nature of schizophrenia has been exaggerated and the fear of patients, their parents and the public thereby increased. Part of this unnecessary mystery appears to be due to a human, though not particularly admirable, unwillingness among many psychiatrists to admit they have become muddled by the obscure and often conflicting notions advanced by the various schools of psychiatry. These schools have been notable above all else for adding little or nothing to our knowledge of this grave illness.

One hundred and twenty years ago, when John Conolly's *Croonian Lectures* were published, psychiatrists who read them were in a position to give a clear and concise portrait of a mental illness with an inherited component, frequently beginning in late adolescence, accompanied by major disturbances in the autonomic nervous system and characterized by a great variety of changes in sense perception which often, but not always, are related to characteristic difficulties in thought, association and mood.

This is a highly recoverable illness for at least one third of the cases have a permanent remission, another third have a remission followed by one or more bouts of illness and the final third are gravely harmed with fewer, shorter or no remissions. Nevertheless, people have been known to recover even from the gravest illness after suffering for years.

Conolly, Kirkbride in the United States, and their many contemporaries and predecessors knew well enough that good, well designed, well administered hospitals with properly trained staff in adequate numbers were necessary for treating patients in their day and getting the best results.

Today we know far more than they did and have diagnostic measures to back their shrewd clinical hunches. We have better treatments, too, although we do not always use what we have systematically and skillfully.

Our greatest error seems to have been that we have taught the public little or nothing about these widespread and most human of illnesses. What they have learned has mostly been to the disadvantage of our patients. Consequently, we have not acquired for them the sympathy and concern which they so richly deserve.

What then is the remedy? It is surely the same as that which has been applied to so many other illnesses which in their time was certainly as mysterious and no less repugnant than schizophrenia. This is to form societies all over the world which devote themselves determinedly and single-mindedly to bettering the care and treatment of those who suffer from this disease, while insuring that sustained researches are undertaken so that it can before too long, be greatly alleviated or prevented.

When Lord Ashley, later the Seventh Earl of Shaftesbury, spoke in the House of Commons on the Lunacy Acts on July 23, 1844, he reminded his audience that "the motion is made on behalf of the most helpless, if not the most afflicted portion of the human race." And in July of the subsequent year when the motion for ordering the bill was at last brought forward he said, "Sir, it is remarkable and very humiliating—the long and tedious process by which we have arrived at the sound practice of the treatment of the insane, which now appears to be the suggestion of common sense and ordinary humanity."

Our patients remain among the most afflicted of the human race. Unluckily it continues to be remarkable and very humiliating that the combination of common sense and ordinary humanity are still rare enough to be remarkable.