Voluntary Action by Relatives and Friends of Schizophrenia Sufferers in Britain

by John Pringle and Peggy Pyke-Lees

Abstract
The founding of the National Schizophrenia Fellowship (NSF) is described as a response to the failure of the professional mental health community to meet the needs of schizophrenic individuals and their families. Since its inception, the NSF has engaged in four types of activities: education, political lobbying, policy formulation, and research support. Examples of each type of activity are given, illustrating the efficacy of such consumer-oriented organizations in coping with serious mental disorders such as schizophrenia.

How and why the National Schizophrenia Fellowship came to be started in the United Kingdom and what it does are described by John Pringle, its President and Founder, and by Peggy Pyke-Lees, its General Secretary from 1974 to 1981.

John Pringle: The National Schizophrenia Fellowship grew out of one young man’s schizophrenic illness and his family’s experience of it. When our B. began behaving in a bizarre way, the most prestigious and venerated university where he was studying did nothing about it for a year. They neither took professional advice nor even deigned to inform us, the parents. They sacked him finally at 48 hours’ notice, because he was shouting insults at tutors and refusing to come out of his rooms. So B. came back home, dazed and bewildered, to an equally bewildered family. Plainly he and we needed help, but how to get it, where to look, and, more importantly, what to look for? Our family doctor—admitted knowing nothing about mental illness. Consulted frantically by letter and phone, the family circle were at sixes and sevens. Some indignantly asserted that B.—the charming and brilliant B.—could not possibly be “ill.” He probably had some adolescent hang-up, they said, and would snap out of it, left to himself. Some thought he must be got away from home, sent “round the world” or to a cousin who was farming in Kenya. (Belief in the therapeutic virtues of travel and the open air lingers on.) Somebody else had heard of a first-class doctor in Vienna (or was it Zurich or L.A.?) who had done wonders for the son or daughter of that friend of theirs.

I got used to this cacophony of voices in the next few years. What family in our position hasn’t? I also got used to living in a fog. I visited mental hospitals which excluded varying degrees of bleakness and pessimism, or perhaps they were only reflecting my own pessimism back to me. I interviewed psychiatrists, who told me different things but mostly tried not to tell me anything. Or so it seemed. I became a connoisseur of the emollient dismissive, “Well, we shall just have to see how we go, shan’t we?” or, with a ghastly smile, “Very important for us to keep cheerful.” In the midst of all this bluffness, my heart warmed to the man who said, “We don’t seem to be doing anything for B., do we?”

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It took 2 years before we got a diagnosis, though looking back it would seem to have been an open-shut case, and many more years before we could obtain treatment or care which made any kind of sense. No doubt at all times and places, systems of medical care are perceived differently by providers and "consumers." In the Crimean War the British War Office was convinced that their supply of bandages and similar comforts for the wounded met all reasonable requirements and that Florence Nightingale was fussing unnecessarily. A hundred years later a similar disjunction between official assumptions about "community care" of mental illness and the reality is accurately described by Peggy Pyke-Lees, who puts our family's situation and problem in the setting of what the "paper aims" were.

Peggy Pyke-Lees: The concept of community care envisaged in Britain by the Mental Health Act of 1959 encouraged psychiatric hospitals to discharge their patients and to empty their beds. It was clearly understood that discharged patients were going to be cared for by benevolent local authorities who would provide homes and hostels, short-term and long-term, supervised and unsupervised, as well as a range of other facilities including day centers, rehabilitation units, and social clubs. A regular income was to be available under a new system of social security to those patients whose disability prevented them from working, plus a rent allowance to those who were not living at home. Arrangements were to be made by the Department of Employment to provide retraining schemes and jobs. What in fact happened? The numbers of beds in psychiatric hospitals was drastically reduced; it became as hard to get into a hospital as, in former days, it was difficult to get out of one. Even those who were admitted had no security of tenure until they were recovered enough for an independent life in the community.

Lack of community care facilities and lack of communication between services meant all too frequently that patients were discharged suddenly from the hospital and that those who had homes to go to, went to them. Many such families were given no prior warning of the return home of their patient; many of them were confronted by daily and nightly problems they had not expected and did not know how to deal with, and in all too many cases there was no communication whatever from hospital to relatives who found themselves unexpectedly looking after a bewilderingly difficult patient. These relatives did not know that there were supposed to be services helping them, and many of their attempts to discover via the family doctor or consultant psychiatrist, or via the social worker or the clerk in the local Social Security Office, met with dismal failure.

In addition to all the other difficulties, there was the fear, shame, and stigma of having at home a relative who could not work or take part in ordinary daily life. Often, the inclination to hide the situation from neighbors and friends, and even from members of the family outside the immediate home, was stronger than the need to get support from those who should have been in a position to help. The stigma is still strong and must have been an important factor in preventing the whole situation about the care of the chronic schizophrenic in the community from being dragged into the light of day until May 1970.

John Pringle: In May 1970 I put together some of our experiences in an article which was published anonymously in The Times. My sole object had been a hope that publicity would stir some very apathetic hospital authorities and others into action. I wanted controversy. I did not get it. What I got was a shower of letters from Times readers with more horror stories, all saying that their experiences had been carbon copies of ours. Many of my correspondents urged that a society or group ought to be formed that was specifically concerned with the problems of schizophrenia and its aftercare. At length, after difficulties of money and organization, a Fellowship was established and fortunate indeed we were to attract Mrs. Pyke-Lees to become our first General Secretary.

Peggy Pyke-Lees: The first task of the Schizophrenia Fellowship was to discover what the facts of the situation were and, to this end, a professional survey was undertaken by Professor J. K. Wing and Mrs. C. Creer into the needs of relatives of sufferers from schizophrenia. Since a continuing aim was to enable people everywhere to understand the difficulties experienced by those who had had schizophrenia and by the families and friends who were caring for them, a series of publications was started. These included extracts from letters shedding light on the experiences of families who were deeply concerned about the lack of
proper accommodation and employment for their loved relatives, whose earlier expectations of independent living in the community seemed to have vanished. They also showed anxiety for other members of the family whose lives had been shattered into social isolation as they withdrew from friends and neighbors because of the stigma and fear attaching to the disease.

An 18-year-old boy was acutely ill in a mental hospital. His parents had not been told what his illness was, or how it was proposed to treat it. They had been refused an appointment with the consultant. The mother, in her distress, took a day off from work and traveled 30 miles to the hospital. She sat outside the clinic where she knew the doctor would be. After she had waited some hours, the doctor came to her and said, “I understand you have been waiting to see me. There is nothing I can tell you. Your son will never be better than he is now”—and he walked away.

With advice from the National Schizophrenia Fellowship (NSF), a second consultant opinion was arranged, and it is good to report that the boy is now out of hospital and doing well.

Much of the original purpose in publishing information about schizophrenia and its effect on patients and their families was to inform the Department of Health and Social Security about the need for improvement in social provision. Professional workers joined the Fellowship in general agreement that the time had come for a reappraisal of the whole situation of provision. This was largely owing to two factors:

• Firstly, that patients quite clearly continue to be disabled, and vulnerable to relapse, even though they have spent only a brief time in the hospital—or perhaps nowadays no time at all.

• Secondly, the rediscovery that “community” (that is, nonhospital) care also has deficiencies, sometimes quite as great as those of hospitals.

Later, there were encouraging indications that the Fellowship’s words were being listened to with attention since the Government White Paper published in October 1975, “Better Services for the Mentally Ill,” indicated in its provisions that the Fellowship’s words had indeed been heard with attention and that their recommendations had had a noteworthy impact. In addition to all the educational work, and based upon it, it had therefore become and continues to be the Fellowship’s task to put pressure on statutory authorities nationally and locally so that they will improve facilities everywhere for the care of schizophrenics.

One publication is worthy of special note. A brief pamphlet simply entitled “Schizophrenia” was produced in response to members’ requests. It emerged that many members only learned many years after the beginning of the disease what the diagnosis had been. No one had ever told them what it meant or what the likely outcome was. They frequently became aware of the diagnosis from reading it on a certificate or from being told by a clerk in the Employment Office or the Social Security Office. A basic statement about schizophrenia was produced which was made available to members. In fact, one of the members sent a copy of this document to the national press where it received a great deal of good publicity and has since had a steady sale, including many requests by professional workers of all kinds—family doctors, social workers, and, more recently, magistrates and the police.

That community care for chronic schizophrenics has to a large extent devolved upon the police and the prison service is not widely known. Patients who have been discharged into the community after a long hospital stay all too often find themselves in the hands of the police and sometimes in the courts. Originally incredulous that a schizophrenic was refused readmission to a hospital which had been his home for 29 or more years, Probation Officers telephone the Fellowship for help in finding somewhere for their client to live which would provide the necessary support. As the Minister of State, Home Office, said in March 1977, “It is no part of a civilized policy to put the mentally ill in prison and to make prisons the receptacles of those whom no other agency in society will accept.” But such is the effect of the policy of community care that, as the “Report of the Work of the Prison Department 1976” pointed out:

Mentally ill people are entering prisons and Borstals in increasing numbers and people of previous good personality, whose offenses frequently stem solely from their illness, are now being refused admission to psychiatric hospitals and are, instead, being received and detained in prison establishments.

In November 1977, Dr. J. H. Orr, the Director of Prison Medical Services, commented on the diffi-
difficulties and distress of the prison service that so many psychiatric patients are finding their way to prison. He went on to say:

... but it was felt that if the prison service was to be effectively dealing with the problem, there would be an even greater reluctance on the part of mental hospitals to accept dangerous and possibly disturbed offenders. There was no doubt that mentally ill prisoners should not be in prison, and should be transferred to hospitals; we should not take steps which might cause people outside to conclude that the mentally ill were in their proper place in prison.

Recent publications by the NSF have drawn attention to this tragic and disgraceful situation.

In “Home Sweet Nothing” (May 1979), the Fellowship has proposed the development of campus communities comprising a range of sheltered environments, where the need for continuity with minimal disruption can be met, and methods of rehabilitation and criteria of assessment can themselves be properly assessed. The desperate need for appropriate residential accommodation for mentally disturbed people was also emphasized in the 1976 Annual Report of the Salvation Army:

An unfair burden has been placed on such organizations as the Salvation Army who always have large numbers of mentally disturbed men and women sleeping in their hostels. The 1959 Mental Health Act opened the doors of mental hospitals to discharge a stream of patients, who without adequate preparation, were expected to re-enter society and cope with the demands of daily living. ... The vast majority became rootless wanderers, unemployable, frequently charged with criminal offenses. Today there are more than seventy thousand people who have been in a mental hospital for a period of two years or more and who have been discharged without adequate provision. ... The Salvation Army does not complain. ... But it does feel most strongly that this great area of social necessity should be examined in depth by the statutory authorities.

The NSF, having attracted much support from professional workers and other national voluntary organizations, plans to bring the campus community concept into existence as a national experiment.

An important part in all this educational process is increasingly being played by people who have had schizophrenia themselves and, often with symptoms controlled by medication, are back at work and ready to speak about their experiences. Such contributions are listened to with great attention, and some of the Fellowship’s members of this kind are becoming more articulate about the sort of help which has been of value to them and any other kind of support which they would have found useful at different stages in their illness.

While all this educational work was going on, the Fellowship had attracted a considerable correspondence not only from people all over the country, but also from all over the world, many of whom were surprised to hear that there were others in situations similar to themselves. Every item of publicity, whether on the radio or television or in newspapers or weekly journals, produced hundreds of letters, many of them describing the writer’s own traumatic experiences and nearly all of them asking for help. Every week therefore, during these early years in the life of the organization, brought increasing demands for help to the Fellowship’s office—the quest for information and advice has grown enormously. Among those seeking help are professional workers in all disciplines, some of whose inquiries are of a practical nature, e.g., housing, or disability benefits, while others are concerned with ways in which it may be possible to help families by bringing them together in NSF groups in those localities where such groups do not already exist. It is, of course, largely because of its members’ own experience that the Fellowship is able to give practical help and make suggestions which, it is now clear, are of value to those trying to find out, sometimes desperately, what should be done to help their relatives and themselves.

Increasingly also, NSF voluntary coordinators (the name given to those people who put members in touch with each other locally) are being looked to for advice and practical help by all kinds of people, not only other NSF members, in their home district. Residential study weekends for voluntary coordinators are being arranged so that plenty of time can be given to exploring the sort of guidance that would be helpful to different kinds of inquirers, and to encourage voluntary coordinators to have a greater belief in their own ability to help each other—in fact, to help them acquire greater self-confidence in what they are doing. This experimental weekend study, with its followup “refresher day” after 3 months, promises well and the Fellowship is grateful to the Mental Health Foundation for funding this experimental project.
The number of local NSF groups has grown, as well as the amount of activity carried out by their members. By July 1979, the number of voluntary coordinators had increased to 135. There is a wide range of local activities from regular befriending of each others’ relatives, to the planning and carrying out of adult education programs, to the organization of local concerts and galas. All these events, carried out in the name of the Fellowship, bring rewarding new contacts in the neighborhoods where they happen, as well as eliciting greater understanding by neighbors and friends. Members in one London Borough arranged among themselves an emergency telephone service, an example which is now being followed in other areas; while another NSF group organized weekly country walks and other outings in which they are joined by their patients from the hospital. A growing number of Fellowship members are invited as speakers to groups of social workers, health visitors, general practitioners, and Community Health Councils as well as to various local voluntary organizations. Some members have had the distinction of addressing meetings of the Royal College of Psychiatrists.

Another type of work now being carried out by the Fellowship is the planning and undertaking of national research projects. The appointment of a fulltime Research Officer led to a detailed examination of the best way to provide long-term accommodation, together with the availability of occupation or employment. As a result of this study the Fellowship hopes to enable the provision of some kind of residential facilities to help in this most difficult of all fields on an experimental and flexible basis (cf. campus community concept mentioned above). Another pioneering task has been carried out by a fulltime adviser/coordinator who worked for two years to oil the wheels of communication between the different kinds of professional workers and families in need. The resulting report, “Tied Together With String,” gives an account of 2 years’ active study of the care available for schizophrenics and for their relatives. The author’s words reflect “confusion, not only in relatives but in many professional workers also.” It is made clear that the isolated suffering, despair, and anxiety of many relatives and patients are not simply the result of psychiatric illness or of living with someone who is ill.

The traumatic experience of accepting a diagnosis of schizophrenia is similar to bereavement or loss in the demands it makes on an individual to make painful adjustments to what may seem bearable.

Those who are responsible for providing health and social services are finding this report of great interest so that it is being read and its implications studied.

Relatives who sincerely feel that a patient is not getting the right treatment... often dare not take action for fear of recrimination damaging future prospects. Their fear is often legitimate.

The National Schizophrenia Fellowship, which is a registered charity, is run by a Council of Management composed of 12 elected members and four honorary officers. Finances are always a difficulty. Members are gradually discovering ways of raising funds, and support has been given by some helpful and generous Trusts. In addition the Fellowship receives a substantial grant from the Department of Health and Social Security.

In any article about the work of the National Schizophrenia Fellowship, it should be mentioned that news of its existence has spread widely to other countries who have read in professional journals of its various publications. Two have been translated into German and are about to be translated into Dutch. There are now national Schizophrenia Organizations in New Zealand and in Australia, both brought into being by members of the NSF. The Fellowship is closely in touch with members in other countries who are trying to stimulate a Schizophrenia Fellowship into being in their own part of the world.

The word “research” is always an emotive one when the great disabling diseases are being considered. Research into the cause or causes of this or that disease is a steady fund-raising motif and not less in this field than in all others. But while the Fellowship takes no part in controversies which rage from time to time about the nature of schizophrenia and the treatment or lack of treatment that should be meted out to it, members have been particularly helpful with the research into the cause of schizophrenia which is being undertaken by the MRC Neurochemical Pharmacological unit in Cambridge. There a study is being made continuously of post-mortem brain tissue from people who have had schizophrenia in their lifetimes. There has been thoughtful cooperation from relatives in letting research workers know of any sud-
den sad event in their family so that arrangements could be made for post-mortem brain tissue to be conveyed immediately to the laboratory. The provisional results of this attempt to identify physical factors in the causation of schizophrenia are of promise and interest.

It is impossible to escape the conclusion that during these last few years there has been a change in attitudes as far as schizophrenia is concerned, and that that change owes a lot to the work of the National Schizophrenia Fellowship in Britain. The fact that so much now is spoken, broadcast, televised, and written about schizophrenia—however inaccurately at times—is creating an interest and awareness that here is a major disabling condition about which society needs to be concerned. Increasingly—but still painfully slowly—people are coming to understand that it is one of the great disabling diseases of the world. With this greater understanding, there will be a more sensitive awareness of problems that arise so that with any luck there will be a preparedness in society to find solutions to the problems caused by this tragic disease.

The Authors
John Pringle is President and Founder and Peggy Pyke-Lees was General Secretary from 1974 to 1981 of the National Schizophrenia Fellowship, Surbiton, Surrey, United Kingdom.