

THE  TIMES

The Forgotten Illness (III)

A voice in the darkness

**Why Marjorie Wallace won't keep
quiet about mental illness**

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SALUTE TO SANE

Schizophrenia is less forgotten now but still a scourge

Schizophrenia is the pain invisible. The devastation it can wreak is all too apparent. It is there in the numberless figures still on British streets, desperate, disorientated, deserted. It is there in the families robbed of children who are sufferers or relatives who have suffered by it. And it is there, along with hope, in the painstaking work of campaigners who have dedicated their own lives to helping those who cannot, because of a devastating mental illness, help themselves.

Sixteen years ago *The Times* helped the launch of the charity which highlighted Schizophrenia as A National Emergency and became known as SANE. This week, in *Times 2*, we mark what has been achieved for the mentally ill and their families by SANE and its dedicated founder, Marjorie Wallace. In so doing, we hope to acknowledge how much has been done to advance the cause of those who suffer from what we then described as "The Forgotten Illness". We also seek to refocus attention on how much remains to be done.

The development of wise policies for the mentally ill has been hampered by difficulties which are no more forgivable for being easily understood. Mental illnesses often pose diagnostic and remedial problems more complex than physical ailments. The absence of immediately obvious indicators and past prejudices towards disorders of the mind have inhibited public sympathy. Schizophrenia was seen as a minor "social malfunction" rather than a devastating mental affliction. A well-intentioned antipathy towards the jail-like conditions of many old mental hospitals encouraged policymakers to move the mentally ill into "the community". But what should have been a process of subtle absorption became the clumsiest of decantings driven by a zeal to save money.

Fighting these impediments to civilised treatment of the acutely, yet invisibly, vulnerable has been SANE's mission. Schizophrenia is not some Jekyll and Hyde tussle which requires either "willpower" on the part of the victim or forcible restraint on the part of society. Schizophrenia is not a matter of split personalities but biochemical imbalance in the brain, its origins a mystery but its treatment getting clearer.

Dealing with the illness has been complicated by the unpredictable fashion in which it can affect its victims, some succumbing briefly, others oscillating in its grip, the most unfortunate never properly recovering. Important work here has been done under SANE's aegis. The general inadequacy of analysis, often so useful in other mental ailments, has been explored. The potential genetic, and chemical, causes have been charted. And in so doing a better understanding of the dangers inherent in "recreational" drug use has emerged. A "cure" remains elusive. But better means of alleviating the pain and dislocation that the condition causes have been established.

A recognition that benign, secure, physical environments can hugely assist those in mental pain has become widespread. And SANE has also secured acknowledgement that for this loneliest of conditions the close, consistent, continuous contact of an individual who cares can aid recovery. There is still much that can be done. The resources allocated to mental health budgets are too small for the scale of the task. The thrust of government policy is, alas, still too much orientated towards helping society against the tiny minority of schizophrenics who can pose a public risk and insufficiently shaped for those many invisible patients, and their families, who suffer in silence.

cover story



MENTAL ILLNESS:
STILL FORGOTTEN?

It is 15 years since Marjorie Wallace forced schizophrenia into the national consciousness, with a series of articles she wrote for *The Times* called *The Forgotten Illness*. As a result she founded the mental health charity SANE and became a thorn in the side of health ministers. So what has changed for those who suffer from mental illness? This week *The Times* and Marjorie Wallace reopen the debate. Here she talks to **Valerie Grove**

Everything has a dark side

Dickens could have invented Marjorie Wallace: in fact, he almost did, in *Bleak House*, in Mrs Jellyby, "a lady of very remarkable strength of character, who devotes herself entirely to the public", whose handsome eyes blaze with passion for a cause to which she dedicates all her time.

I don't suggest that Wallace neglects her home or her children, as Mrs Jellyby does for the natives of Borrioboola-Gha on the left bank of the Niger. But ever since she wrote a series on schizophrenia called "The Forgotten Illness" in *The Times* 15 years ago, and the resulting charity SANE (Schizophrenia: A National Emergency) was founded, she has been the campaigning journalist whose campaign took over her life.

Few journalists manage to influence events: most dip into human predicaments, describe them and pass on. But Wallace discovered a rapport with schizophrenics and their suffering families, and stuck by them. Mental hospitals were being closed and

"care in the community" was proving to be, as she puts it, a small tent in a hurricane. For successive health ministers — from Owen through Clarke to Milburn — she became a thorn in the flesh, as Virginia Bottomley said in the Commons. Yet all have heaped praise and gratitude on her.

If she often wears the piteous mask of a tragic heroine — some friends refer to her as *La traviata* — there are good reasons. Such as years of imploring and wheedling to raise the funds for SANE and its telephone service, SANELINE. (Their income from donations, she says, is on a level with that of the Donkey Sanctuary.) Now at last the building of her dreams, SANE's Prince of Wales International Centre for Research into Schizophrenia is newly completed in Oxford. Here scientists will, she is certain, one day fathom the unfathomable mysteries of schizophrenia and manic depression.

This has been achieved against all odds. Seven years ago Wallace discovered that she had breast cancer. She lost her hair during chemotherapy, but

simply bought some pretty hats and carried on fundraising harder than ever.

Professor Anthony Clare, in *In the Psychiatrist's Chair*, tried to discover what drove her on: "You could, without loss of respect, have stepped down from SANE and said 'I now have my own life to live'. You have an MBE. You have raised millions. You have kept the love and affection of your children. You have survived a difficult marriage and are coping with a severe illness." Clare kindly reminded her. "And it's not enough to give you hope and sustenance?" Wallace: "No it doesn't."

Although she has written several outstanding books, she yearns to write a great book, for the sake of immortality. "What I'm doing is so short-term," she says.

The past five years have been tough, punctuated with precipices and plateaux in her state of health. There was another precipice last year, with a life-or-death decision to make. She went to South Africa on holiday, and might almost have been seduced by landscape, flowers, sunlight. But, flying over the Sahara, she

remembered the people to whom she has dedicated her life, and concluded that paradise was not for her. Besides, she has always opted for the road less taken. "People with psychosis are extraordinary, and it's such a challenge to get into the mind of someone experiencing what you might call madness."

"You wonder what it is like. How does it feel? Why do they hear this cacophony of destructive, punishing voices? Delusion is very powerful. Mental illness is like your mind being taken hostage by your brain. And you are kidnapped, hijacked, and no longer have feelings, thoughts, perceptions. Someone has to break that siege. The mind battles to survive something worse than Gestapo torture."

So Mrs Jellyby persists. She was writing a speech last weekend when men arrived and erected scaffolding on her Highgate house: her sweet-natured partner, the scientist Dr Tom Margerison (of whom she says: "He is my brain; without him I would have no courage") had not dared to tell her, knowing how busy she was, that the builders were coming in that day.

She was born in Nairobi, in the very house in which Karen Blixen wrote *Out of Africa*, where, as she picturesquely describes it, "the colours were dry and burnt, like the colours in pottery". Her father, a civil engineer, built railways, dams and bridges, until he went blind from malaria. Mother would practise on her piano, even in the bush, for two hours every day. After they came home to England, her school reports described Wallace as a dreamy child. She dreamt of being a pianist, and gained a Royal Academy of Music scholarship. But instead she read philosophy and psychiatry, and joined the BBC and then *The Sunday Times*.



One of Marjorie Wallace's pieces about schizophrenia in *The Times* from December 1985

SINEAD LYNN



Marjorie Wallace: "I don't have boundaries between my life and the people I write about"

She married a Polish Count, Andrew Skarbek, a consultant psychiatrist: what impressed her most was that Chopin was born in the Skarbek family's house at Zelazowa Wola, outside Warsaw. Chopin's *Polonaise in G minor* is dedicated to Wallace's namesake, the Countess Skarbek. (That house is raw, by coincidence, a mental hospital.) For 17 years on *The Sunday Times* she pursued harrowing stories, accompanied by Lord Snowdon snapping away. They carried out "dawn raids" on mental hospitals; they sought out the mentally ill who live on the streets and

other Dickensian underworks. "Snowdon and I made a dedicated, if somewhat volatile, team," she has written. When he did Wallace's portrait he dressed her in a velvet cloak and insisted on an imperial stance. As a campaigning journalist, she could never be objective. "I always get involved; I don't have boundaries between my life and the people I write about. If you use people's thoughts and diaries, you have a responsibility to be there if they want to keep in touch with you. Schizophrenics are my top priority." [The series she has written for *The Times*

this week, revisiting her original case histories, reveals how closely in touch she has remained while they have grappled with life in "the community".] "They thought that everybody would be free and normalised and liberated if you threw them into the community: 'Come to our day centres and thread beads.' But communities were paper walls, unable to take this burden of the dark side of humanity." When in need of consolation and respite she finds it in her own well-stocked brain. She will study a favourite Requiem until

she has it by heart. She carries Eliot's *Four Quartets* everywhere, along with lines that she has memorised: Walter de la Mare's "Look thy last on all things lovely, Every hour"; Emily Dickinson's "I died for beauty"; Hopkins's sonnet "No worst, there is none". She re-reads Lara's farewell from *Dr Zhivago* (she gave her children Russian literary names: Sacha, Lara, Stefan, Maximilian). Naturally, she made an excellent subject for *With Great Pleasure* on Radio 4, and Michael Berkeley's *Private Passions* on Radio 3. She loves Victorian par-

'The richer, the meaner. The people who really give have no money'

lour ballads, the sicker the better: she will sing you *Father, dear father, come home with me now* by flickering gaslight if you promise a handsome donation to SANE. She once raised £50,000 at an auction in this way.

But fundraising is a humiliating treadmill. She says the *Monty Python* sketch in which John Cleese plays a tycoon wrestling with the concept of giving a pound to a collecting tin for orphans — "I just don't get it. I mean, what's in it for me? Seems a pretty poor investment" — accurately reflects the tightfistedness of the rich: "The richer, the meaner," she says. "Name any rich person and I'll tell you."

I named one. "He gave a little blood sample out of his stone. But the people who really give have no money; people on benefit who send £5. The jet-set world is like clouds of butterflies. They swarm from one party to another — New York, the Greek islands, wherever the party is — and charities are part of their circuit. They never know what charity they're giving to, but if you catch one, you get the whole crowd. Half my life is spent trying to fly with the butterflies. But I don't have the money or jewellery."

She concedes that good things have happened in the past 15 years, and that some people are better served. There is a place in Gray's Inn Road that recognises how important pleasant surroundings are; there are also acute wards with what she calls grim dirty dishcloth decor.

"But, then, not everyone wants the kind of place we call pleasant. We have tried to equalise everybody. We don't allow for variation of personality. To be a mental-health service user now, you have to conform.

"Tick all the boxes to get your care plans. The route to recovery may not be drugs, but consistent contact with one person who cares — that is the most repeated cry of need.

"These people are fragile, the boundary is fragile. One day you are having a sunny lunch with a former patient and he seems fine; the next day he's manic, menacing people, and he's back in an acute ward.

"Some people are desperately ill but are being treated as if they had a minor social malfunction. When I started, 90 per cent were voluntary patients. Now about 70 per cent are sectioned, coming into acute wards through the courts, through the police. Most of them are high on drugs, cannabis, cocaine, crack." Not surprisingly, Wallace is totally against legalising cannabis.

Though her scientific background is non-existent (O-level physics, failed) she now has an impressive grasp of neuroscience. She is an honorary fel-

low of the Royal College of Psychiatrists. Professor Colin Blake-more says she is ahead of the experts in her openness to new approaches to psychosis. "There will be more breakthroughs. It's not a condition that we're going to have to live with for ever."

The Oxford building, by the architect Demetri Porphyrios, is more exotic than she had imagined, with an atrium of Jerusalem

limestone, and Moorish fountains and floodlighting; sponsors are now being sought as she plans an Islamic water garden — a tribute to the Middle Eastern donors, based on one the Prince of Wales devised for Highgrove. There will be a bridge of hope over a canal, with irises and waterlilies. Inside, along with laboratories and seminar rooms, there is space to hang creative works by former manic depressives, and a stained-glass window created by a schizophrenic.

"Buildings don't generate cures, but I think that they generate hope. They show that people are prepared to invest in that illness in bricks and mortar, and find the cause of psychosis, which remains the Mount Everest of challenges."

Under Professor Tim Crow, 37 papers were published last year by the centre in its temporary home in Oxford University's department of psychiatry, covering hypotheses concerning genes, heredity, chemicals. (It is unlikely to be one single gene, says Wallace. And about 30 per cent of cases have an element of heredity.) Overcoming doctors' powerlessness is the spur. "NHS psychiatrists believed that any kind of illness could be dealt with by analysis, but they couldn't cope with schizophrenia. They asked, who is to blame?, and pointed to the parents. If I could say I've done some good in life, I've helped to lift the blame from parents.

"SANE can't give back souls and brains, but we can give comfort to the comfortless. A thousand people a week call SANE's helpline, which is my proudest achievement. It brings relief and consolation to those who feel isolated and full of guilt and fear — people such as Sheila Silcock, whose son Ben climbed inside the lion's den."

Then Wallace adds: "But you have to ask, would we live in a society without madness? Everything has a dark side; maybe this is how we pay for all the goodness, beauty, the wonder of life."

About her own illness she is not so philosophical. "I am less accepting than before. I used to feel that I had to stay still, so as not to wake up the evil cells. Now I'm running everywhere. I guess to escape the Furies for another day. I escape all the time, I'm Houdini. Like life on the run. "Tricking Fate." ●

Tomorrow

Marjorie Wallace revisits acute wards for the mentally ill

reportage



MENTAL ILLNESS:
STILL FORGOTTEN?

My anger at the lack of change

Fifteen years ago I set out on a journey to investigate the care and treatment received by people with mental illness. Why was mental illness so obscured by secrecy and stigma that neither patients nor their families dared speak about it? Why, when it can have such a destructive impact on one in six of the population, was it being given such low priority? Why were the drugs used so imprecise that many patients preferred the torments of their symptoms to the shaking, slurring of speech and thought and the feeling of being "knocked out" commonly experienced as side-effects of their medication? Why were there only skeletal budgets for researching the causes and better treatments of schizophrenia and depression? And above all, what collective insanity had created a policy called "Care in the Community", which demanded the wholesale demolition of the old psychiatric hospitals before providing alternatives for those too ill to live on their own? This collision

Fifteen years after the Times articles that led her to found the mental health charity SANE, **Marjorie Wallace** has reopened the debate on the mentally ill. In a new series, she revisits the sufferers she first met and searches for signs of progress

between overoptimistic idealism and bureaucratic parsimony created the "abandonati" of the 1980s, people carelessly decanted from hospitals into seaside bedsits, backstreet hostels, shop doorways, or returned to families who had been given no help or preparation, let alone information. These families, in turn, became caught in the crossfire of tensions and frustration which all too often destroyed both them and the person they were left to look after.

It was the exhaustion and disappointment of so many families and the despair of those with nowhere to go that spurred me to write "The Forgotten Illness" articles, which in turn led to the

formation of the mental health charity SANE. In those articles I described feeling like a war correspondent reporting on the displaced and disregarded.

It is clear that although some campaigns have been won, the war is not yet over. In the past few weeks, I have returned to the people I met then — patients, carers, psychiatrists, nurses, social workers, housing officers and others — and have felt a mixture of hope, admiration and downright fury at how much and how little has changed.

There is no doubt that the new atypical medications, which have different but generally more tolerable side-effects, can transform the lives of some individuals. So

too can psychological therapies, the "quiet revolution" in psychiatric care, and teams who work in partnership with individuals, agreeing with them care plans and crisis directives. The social and medical models of care are now less in conflict and the professions are collaborating more flexibly to offer holistic care.

The users and carers have won many of their rights to be consulted about their treatment and to share a voice with the professions. Among the public there appears now to be greater awareness of — and compassion towards — people with mental illness and their families. There has been more sensitive reporting in the media and, despite too

many damaging "psycho killer" headlines, more willingness to help charities like ours to tackle stigma. Politicians in successive governments have shown more interest. I never envisaged 15 years ago that mental illness would become one of the Government's three health priorities, alongside cancer and heart disease.

But far too little has been done to compensate for decades of undernourishment and mismanagement which has continued to short-change the lives of so many. Community Care was implemented not by artists of the troubled mind but by cowboy builders whose job was to minimise local costs with little regard

to the national plan. We are now faced with so many cracks, incongruities and misinterpreted guidelines that the original vision has been obscured.

Whereas 15 years ago we were told that we only had to wait for the gaps in care to be filled, we now find that the pieces of the grand design are not only missing but were never cut to fit. They had been clumsily carved around the budgets and boundaries of health and social service authorities rather than individuals.

Contributing to this shambles has been the waste of old hospital sites. More than a hundred have been demolished or sold, but only a tiny percentage of the proceeds has gone to improve community mental health services. Instead, the profits have been seized by property developers and the Treasury — a daylight robbery that has deprived mentally ill people of their rightful inheritance.

The old-style asylums I visited then have been mainly sold and are either left derelict or turned, ironically, into expensive flats or supermarkets. They have been replaced by acute wards in general hospitals or newly built brick boxes sealed by thin lips of grass from main roads or in rundown areas. Inside the wards, disturbed individuals crave space and refuge, but in these cramped conditions it is impossible to escape either the turmoil in your own mind or the distress of others. Inevitably, cabin fever breaks out.

Occupancy rates in some wards run as high as 140 per cent. This means that patients are shunted from bed to bed, sleep on chairs, are sent on leave and either not admitted or discharged when extremely ill. Usually they are returned to lodgings to await visits from a member of the community mental health team who has no option but to keep them at home.

Unsurprisingly, professionals can become demoralised. Burn-out takes an average of two years and replacement staff are almost impossible to find. There are currently almost 400 vacancies for consultant psychiatrists and a critical shortage of nurses.

Among the hospitals I revisited recently was the Royal South Hants Hospital, Southampton, where conditions in the acute psychiatric unit have become, if anything, worse. Plans to relocate

Daniel: People like me need beauty



Daniel: "I think the whole idea of community care was a big mistake"

Daniel Levy came into my life nine years ago, when he trained as a volunteer on SANELINE. He is now 43 and much battered by years of fighting manic depression. The most obvious sign of his long illness is an inability to control the movements of his legs and arms, a Parkinson-like side-effect of the drugs he takes.

A recent breakdown and bout of depression has left him looking rather thin and sad. This breakdown was caused, he believes, by an attempt to change his medication to one of the newer drugs which did not agree with him.

"I was too ill to do anything but sit around," he recalls. "I was afraid the staff would beat me to death or boil me in hot water. I believed that I was the Devil and Hitler."

"It was terrible in the hospital. The unit at the Central Middlesex is badly designed. There are far too many people there and it's surrounded by main roads and industrial estates. I used to stay at Shenley Hospital in Hertford-

shire, but they closed it. They don't understand the need for people like me to have beauty and gardens. Shenley was like a little town, full of interest. There were cricket fields and tennis courts. It was cruel to take this away from us."

Daniel, who before his illness was a lawyer with a degree from Oxford, analyses the impact of changing mental health policies with cynicism. "No one realised how expensive care in the community would be. The public wasn't educated to have people like us among them," he says.

"I'm lucky because I have my family to help me, but for those breaking down for the first time it's as difficult as when I was first ill. Doctors still won't see someone unless they come and ask for help, and it's the people who don't ask who need it most."

There aren't the homes and there's nothing to do. People I know spend all day walking the streets. We need much more structure and more intensive care. I think the whole idea of community care was a big mistake. I've a flat, but I find it difficult to live alone."

GILL ALLEN



Mental patients have lost their places of refuge and recovery. The profits have gone to property developers and the Treasury

Community care was carried out by cowboy builders to minimise local costs

the unit have not materialised. It remains on the second and third floors of a 1970s building adjacent to the general hospital. The main view is of an incinerator and rows of waste disposal bins. Inside, in spite of clearly committed staff, the atmosphere is disturbing: haunted figures, mainly young men, sit in institutional chairs or shuffle through to the smoking room. They remind me of the house ghosts in the film *Truly Madly Deeply*, lost spirits clutching at a fading reality, overstaying their lack of welcome.

"We have two patients who have been here since 1999 and nine waiting for supported accommodation in the community," says Professor David Kingdon, a highly respected consultant. "Southampton has huge problems: there are not enough community health workers, no crisis resolution team, limited out-of-hours services, and people have to wait too long before they get help. We send people outside the area, not just because of the bed situation, but because of the difficulty of finding hospital hostels and supported accommodation."

As we talk, an agitated young man comes up and explains that he has to get out as people are drilling through the walls into his brain. Kelly watched his mother die of cancer when he was 17 and has never recovered. He looks gaunt and frightened. "This is the only place I feel safe," he says. He is sitting in one of the dormitories, among the most dilapidated I have ever seen, with ragged curtains and separate beds where there are few possessions and no decorations.

So what has happened to the reforms and new morales the Government has given and pledged? According to Professor Kingdon, the public safety agenda will mean that a considerable amount will be spent on secure beds, still leaving out those who do not have a florid illness but may be equally at risk of harming themselves. Despite the pressures and conditions, Professor Kingdon is optimistic: "It is still possible for people to come into hospital and do remarkably well, but we could do so much more. We need to offer more therapy and structured activity."

Like other psychiatrists I talk to, Professor Kingdon is concerned by the high increase in the use of illegal drugs and the impossibility of enforcing a no-drugs policy on the unit.

Professor Sir David Goldberg, Professor Emeritus at King's College London, agrees that this is the most alarming change in the past 15 years: "Fifteen years ago the illegal drug problem was contained, now it is out of hand, making patients more ill and aggres-

sive, and taking away resources from other people."

Jimmy Glass, a locality manager for East London & The City Mental Health Trust, is also concerned by the widespread use of street drugs which has made many acute units rife with drug dealers and their vulnerable clients. Like most people I have talked to, he feels that although community care has improved the lives of the majority of people with mental illness, we have lost the notion of asylum at times of crisis. The revolving door between hospital and the community, which worked well for many patients, has now closed. In-patient care in many areas is at such a premium that unless you can afford it yourself or persuade your Trust to ship you to a private hospital, you will be placed on a ward where, as one doctor told me, only people so ill that they are unaware of their surroundings can bear to stay.

Professor Louis Appleby, the national director for mental health at the Department of Health, admits that in-patient care was the "inadvertent" victim of the shift to community services and that conditions in many units are dreadful. He points out, however, that last year the Government gave the largest grant ever for refurbishment, which will not reach most authorities until next year and will not cover every unit. But he resists creating separate "ghetto" wards for those on street drugs and is instead providing guidelines.

"We do not need more in-patient beds," he says. "This is a blinkered view. There are too many people in hospital who could be better off at home if there were enough support."

Professor Goldberg is sceptical. "We have been waiting for sheltered accommodation and support in the community for as long as I can remember, but local authorities have never been able to afford it."

"Community care is reaching its worse crisis yet — we do not have the beds or trained staff. It is impossible to run a mental health service unless you have empty beds behind you."

Professor Appleby thinks many of these problems will be solved by the new National Service Framework. "I don't want to give a hollow positive view, which goes against the evidence of your eyes," he says, "but I genuinely believe we're on the brink of a major transformation."

This kind of optimism has a sadly familiar ring. But is it not just in my eyes that the evidence lags behind the dream. SANE's helpline, SANELINE, listens to on average a thousand callers a week, whose distress and frustration echo the old loop of neglect: desperate people and families who fall between the planks of government strategies.

The Government says that it offers ranges of options but there is no option for those who would choose a hospital bed or place of refuge. The old idea of helping people in breakdown by metaphorically putting the "mind in a splint" — giving time and space for healing — has disappeared.

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reportage

We should make good

Continued from page 5

Today there is a DIY approach — you take the pack and pills and bandage your own nightmares. It is up to you to take responsibility for your illness. What appears to have happened is a dumbing-down of community care. Not everyone wants to be assessed by swarms of workers visiting their homes, and many people I have talked to find the care offered at many day centres or group homes unsatisfactory and demeaning. But it is the families who feel any revolution in care has passed them by. One of my first staging posts 15 years ago was a group of carers from Yeovil, a place selected as a model of good practice. When I went to see them a few weeks ago, it seemed that the modernisation of services had done little to lift the burden of care. They are the lost tribes, the true casualties of careless swings of policy.

To balance these sombre stories, however, I have come across many people who, 15 years ago might have been condemned to a life of enduring disability, but who are now stabilised. Much of their transformation has been due to the more targeted medications, psychological therapies and, above all, their courage in managing their own symptoms. But no amount of palliative effort can give people back their minds and souls, and the

conclusion is stark: it is the relentlessness of some mental illnesses that presents the greatest challenge. We do not yet know the causes of schizophrenia and manic depression. We know there are biochemical changes in the brain associated with the distortion of a person's thought and mood, but we have not given the infusion of funds and imagination of research, which still falls behind that invested in cancer and other similarly major conditions.

It is not only medical but social research that we need to avoid the mistakes of the past.

One enduring image from this last journey has been that of a girl on a bench amid overgrown thistles surrounded by rusting machinery and discarded bedsteads in the wasteland that was once an asylum. Opposite is what used to be the main entrance to the hospital, now strangled in creepers. On what was once a ward veranda, armchairs were still arranged in a semi-circle with nettles growing about.

We should now make good our neglect of mentally ill people and ensure that we do not leave such a dark legacy as these old models of treatment, and the casual way in which they have been allowed to crumble, without providing alternative refuge and care.

SANELINE: 0845 7678000
Noon-2am daily



Lorraine with her mother Marilyn, who says: "We live on the edge of a precipice and have no confidence in the future"

Tomorrow what the professionals think

THE TIMES

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I first met Lorraine Lazarus when she was 24. She had been severely ill with variously diagnosed personality disorders and schizophrenia since the age of 17, when, in the middle of a family Sunday lunch, she had run upstairs screaming with a pain in her head. From then on she alternately punched, kicked and terrified her family and lived in and out of hostels, homes and a police cell.

Her mother Marilyn used to dread the telephone, knowing that on the line would be someone telling her of a suicide attempt. She and her husband Alan were told by social services that they had to cut themselves off from their daughter and not answer the phone.

They would play back the answer machine to hear distraught messages: "Dad, it's me. I don't know what to do. I've gone insane. I need you and Mum badly..."

Two years after my first visits to the family, Marilyn rang me. She was highly distressed. Lorraine had been living in a therapeutic community, where she had been encouraged to stop taking her antipsychotic medication and, as part of the therapy, the family had been barred from seeing her.

She was now seven months pregnant but, according to those running the community, able to exercise her rights not to have ante-natal care. She had been taken to another hostel, where she had kicked a member of staff and now, on a Friday evening, social workers had driven her to Southall, West London, and

Lorraine: I've gone insane. I need you and mum badly

left her in a bed and breakfast, refusing to give her parents the address.

I drove with Marilyn and Alan through Southall early the next morning. Eventually, through knocking on doors in this hinterland, we found her, naked from the waist up, standing at the top of the stairs in a hotel. Her possessions were in a binliner beside her.

She was talking to voices in her head and seemed unaware that she was pregnant. It was a dreadful place to

dump a sick animal, let alone a disturbed girl. We drove Lorraine to Northwick Park Hospital, where she was given treatment. Two months later her son was born in hospital and taken away to be fostered. I filmed Lorraine and her baby shortly after the birth for a BBC documentary.

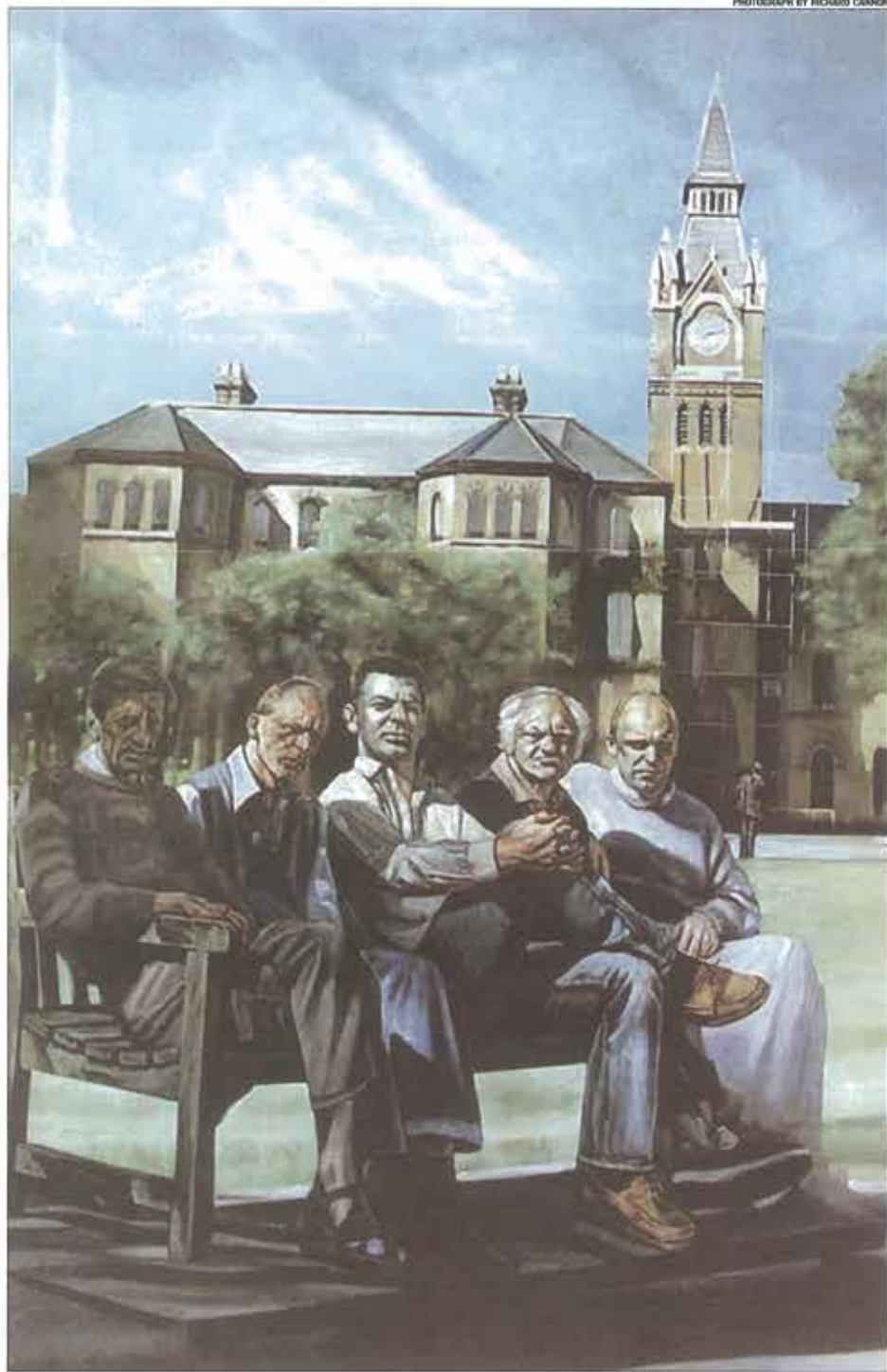
Last month I was invited to the bar mitzvah of Lorraine's son. After his birth, Marilyn and Alan, who wanted him brought up in the family, had endured a financially and emotionally bruising custody case, which they eventually won. It was always recognised that Lorraine was far too disabled to look after him, however he knows her as his "tummy mummy".

Lorraine is now 40 and, in many respects, her life has improved. Her parents helped to raise £1.5 million to build a residential home, one of the very few that provides mentally ill people with their own ensuite rooms and where there are no rules to evict guests if they become disturbed. It is a spectacular achievement, but Marilyn says: "We still live on the edge of a precipice and have no confidence in the future. It should never have been left to us to build a house so that Lorraine has somewhere to live when we're gone. It has been the wickedest, cruellest experience — this illness — and it has devastated us."

"Lorraine is lucky because we're fighters," says Alan. "But we've seen families split up and people die. The mentally ill are given second-rate facilities. It's all promises and no action."

our neglect of the ill

PHOTOGRAPH BY RICHARD CANNON



Paul's painting shows him and four friends at Brookwood Hospital, Surrey, once a place of refuge and now closed

Paul: Part of my ward was sold as a luxury flat

Paul is an ebullient, charismatic man in his early forties. He is also a powerful artist: his painting *Barney Days* hung in the National Portrait Gallery and is now in my living room awaiting its final place in SANE's newly completed Prince of Wales Research Centre in Oxford.

Barney Days is a portrait of Paul and four friends, all former patients at Brookwood Hospital, Surrey, which, along with more than 100 other psychiatric hospitals, has been closed. "I wanted to show the positive side of the mental hospital and the way it allowed us the time and space to accept our illness. The sad part of the picture is the little figure on the edge of the lawn: if he crossed into the community he would be lost for ever," he says.

Paul had a traumatic childhood and became acutely psychotic at the age of 15. Brookwood was the safe haven which he is convinced saved his life. "The worst part is the mania, spiralling out of control," he recalls. "It can be terrifying, like a knife in the head. I did crazy things. I'd disappear on the streets for months at a time. I attempted suicide and then I would be back in Brookwood. It was a brilliant setup, and heartbreaking that they have destroyed it. Part of my ward has been sold as a luxury flat for three-quarters of a million pounds, and now people like me have no sanctuary.

"Community care might have been a good concept, but it can be very lonely. In Brookwood, local people were always coming in to dances and other events. You were never isolated."

Now Sebastian, one of the friends Paul painted in *Barney Days*, sits all day on a bench in the high street. Others have disappeared, and five people Paul knows have committed suicide. Paul himself was admitted to an acute unit three times earlier this year, twice "sectioned" under the Mental Health Act. He had been picked up by police after screaming abuse in the street and threatening others with his paranoid delusions. But living in the unit only increased his distress.

"It's very claustrophobic," he says. "It's not a patch on Brookwood. We were on the second floor overlooking a car park and hospital chimney. The only garden is a patch of green with a big fence, which we couldn't reach much of the time as the



Paul: artist and patient

door was locked. I longed for the trees and grounds. There was no peace anywhere."

Paul's wife Lorna, a former psychiatric nurse, wrote to the director of mental health for the Surrey Hampshire Borders NHS Trust in March. In her letter she said: "I am horrified and outraged by what I have seen in the past few days. My husband has a Z-Bed in a review room, surrounded by stacked furniture. Another patient has another mattress on the floor in the same room. I would estimate that there are ten more patients than there are beds. This is quite simply dangerous and could lead to tragic results."

I went with Lorna and Paul — who is currently in good health — to visit some friends he made who were still, months later, on the ward. Some were in pyjamas hunched in institutional chairs, a few were playing a desultory game of pool, and Paul's friend was sitting alone in the sordid smoking room, where there are no pictures on the peeling walls and just a glimpse of the sky through smeared windows.

It is difficult to see what this cramped and shabby unit offers such disturbed men, and why it should be considered preferable to the grounds, theatres, canteen and facilities of Brookwood where I had wandered with Paul seven years ago.

Paul dreads getting high again and having to return to what he feels is his prison. "When I am a year down the road of being stable," says Paul "I'll accept that I can control this illness and it doesn't control me."

reportage

Fifteen years ago Norman Fowler, the Secretary of State for Social Services, assured *The Times* that the profits from the sell-off of the country's old Victorian asylums would be used to create a modern community-based mental health service.

More than a hundred mental hospitals were closed under the move over to Care in the Community and the often substantial grounds of many were converted into upmarket housing developments. Just 3 per cent of the land was retained for the health service.

A decade and a half on, a new survey of the country's psychiatrists has found that many believe that Care in the Community is still starved of resources and that the closure of long-stay beds went too far. Britain's psychiatrists complain most bitterly about the broken promises of successive governments, the lack of resources and the deterioration of in-patient care.

SANE, the mental health charity founded in 1986 to campaign for better treatment of patients under Care in the Community, found attitudes hardening at this year's Royal College of Psychiatrists' annual conference.

Its survey of 70 of the delegates paints a sorry picture of a Cinderella service which is failing too many patients — despite many advances in treatment which offer greater hope to sufferers of mental illness than 15 years ago.

Nine in ten psychiatrists believe that there has been a gap between ministers' rhetoric and the reality of progress on the ground, the survey found.

The findings will dismay the Government, which has made mental health one of its top three priorities alongside cancer and heart disease. The trouble is that no one seems to have noticed. An awareness campaign, "Mind out for mental health", has so far passed most people by.

Plans for a new Mental Health Act were dropped from this year's Queen's Speech. Ministers have promised an extra £300

Progress? There is none

A survey by SANE has found that many psychiatrists are unhappy with the underfunding in mental health services. But, says **David Charter**, low morale may be a greater problem

million annually under the National Service Framework for Mental Health.

The psychiatrists were asked: "Do you find that there is a gap between the rhetoric and pledges in recent years and the reality on the ground? How would you define it?"

Many of the responses were blunt. For example:

"Where's the money?"
"My energy and commitment are the same, my frustration is more and demoralisation is increasing."

"The emphasis is on looking good... rather than being realistic. Politicians lie all the time."

"There is little correspondence between Government statements and what actually happens on the shop floor. New money is only invested in new (and untested) services while core services are still neglected."

Some services have improved but only patchily, the SANE survey suggests.

Answers to the key question: "Have mental health services improved over the past 15 years?" were mixed.

While 51.4 per cent perceived an improvement, 24 per cent said



**MENTAL ILLNESS:
STILL FORGOTTEN?**

that there had been none, while the remaining respondents cited partial progress.

In response to the question: "In what ways do you consider that people with mental health problems have been helped/fared the most?" there was overwhelming support for advances in treatment but total condemnation of lack of resources.

The new generation of atypical drugs used for schizophrenia, which target the condition much more precisely and have far

fewer debilitating side effects, are widely seen as a great advance.

Unfortunately, their accessibility remains a lottery as some health authorities refuse to pay the higher cost when traditional anti-psychotic drugs are more cheaply available. These, however, cause dramatic side effects, such as spasms and dribbling, which add to much of the stigma already surrounding mental health conditions.

Lack of staff and beds were the greatest resource concerns voiced by psychiatrists. One commented: "Positive developments have been severely hampered by low investment and asset-stripping."

Almost half the psychiatrists (46 per cent) reported a deterioration in the quality of in-patient care since 1986, with two-thirds (67 per cent) saying that more funding was needed. Patients need better facilities, more beds and more positive activities, the psychiatrists said.

Most worryingly, 30 per cent believe that the quality of community care has got worse since 1986, with 13 per cent saying that it has not changed and 37 per cent perceiving improvements.

The remaining 20 per cent did not respond.

Marjorie Wallace, the chief executive of SANE, says: "It is surprising that so few psychiatrists have said that things have got better. It is utterly shocking that in 15 years when we have been given so many promises and pledges, and we have led people to believe that there has been a huge improvement in mental health services, that so many psychiatrists think in-patient care has deteriorated."

"The picture is of run-down places where people no longer have anything to do. There is no structured activity."

"It is even more shocking to find that 30 per cent believe that the quality of community care has deteriorated, because the money was supposedly taken out of in-patient care to make that better. This is an indictment of the whole Care in the Community system." Professor John Cox, the president of the Royal College of Psychiatrists, says that the SANE survey accurately reflects views within the profession.

He adds: "I know that in-patient facilities in three-quarters of

mental health services are really inadequate. There are places where acute in-patient units are just not therapeutic because the physical environment is awful."

"There is a lack of nursing staff and a shortage of consultant psychiatrists. There is a 14 per cent consultant vacancy rate."

"It is crystal clear that one needs highly staffed in-patient care units to balance community care. You need both, and both are expensive."

"There have been positive developments — community-based mental health teams are the norm across the country, as is increased expertise in various psychological treatments."

"We are really at a watershed. This Labour Government is intending to rescue the NHS and over a ten-year period, given the will to do it and the funding, that could happen."

But one of the country's leading consultant psychiatrists working with people with schizophrenia, Adrienne Reveley, the clinical director of the Psychosis Unit at the Bethlem Royal Hospital in Beckenham, Kent, is not so optimistic.

As she sees it, "the big difference between 1986 and 2001 is that we are now a demoralised profession". She also works as a consultant psychiatrist at the Maudsley Hospital, London, and finds patient after patient bewildered after seeing a succession of locum psychiatrists.

Dr Reveley is frustrated by the discontinuity in care experienced by so many psychiatric patients, not least because advances in treatment mean that they have a better chance of recovery if their illness is caught early and dealt with consistently. "You get situations where patients have had locum after locum after locum. At least 50 per cent of the patients I see have got problems with provision of care," she says.

"There are improvements, in terms of our knowledge about illness. But there is a lot of unhappiness, much of it due to the patchiness of the service." The

Self-harm and suicide



The level and intensity of calls the charity receives is higher than ever

Hannah was seven weeks old when she started having epileptic fits. Medication stopped the convulsions but now, aged five, she has become aggressive — swearing, biting and throwing herself down the stairs. She finds common sounds, such as a lavatory flushing or a lorry passing, disturbing. She says she wants to die. Susan, her mother, has been told that Hannah is not autistic, nor does she have attention deficit hyperactivity disorder. She is desperate for help. At the other end of the telephone, a counsellor from SANE, the mental health charity, listens to her and gives Susan contact details for support groups.

In the 15 years since SANE

was formed to campaign for greater awareness of schizophrenia, one of the most noticeable developments has been the growing number of calls from parents. Marjorie Wallace, who founded SANE after writing a series of investigations for *The Times*, says that the level and intensity of calls the charity receives is higher than ever.

"Their GPs are not taking them seriously. They dismiss the children's behaviour as a parenting problem, or say it is just adolescence starting," she says. "You can understand doctors not wanting to label someone schizophrenic so young — but that is when they need to be treated."

One theory behind the emergence of reported symptoms among younger children is that

mental illness is less of a taboo subject than it was 15 years ago. And advances in drug treatments and therapies mean that doctors have a much better chance of controlling mental illness, especially if it is recognised early. But sufferers and carers of all ages say it remains frustratingly difficult to convince the official services that they need help.

SANELINE's log has details of Gwen, who suffers from depression. Gwen "has attempted suicide several times in the past year and is struggling to come to terms with childhood abuse. She has no contact with her family, which she finds distressing. She has been waiting to see a psychotherapist for 18 months". Another caller, Tracy, "keeps cutting herself. It has got to the point

where she feels unable to control it. She has told her GP, who was not helpful and said it was common and that as long as she was not suicidal, she was OK."

In such cases, SANE offers a call-back service, which can involve ringing back weekly or even daily at appointed times. For some callers, this becomes a lifeline — one said that he did not always pick up when SANE rang, but knowing that it kept the appointment stopped him from overdosing.

Self-harm is common and SANE believes that the seriousness of injuries is worsening. "Whereas a few years ago we heard of girls taking a small overdose, now they burn themselves with cigarettes, cut themselves or wash in bleach," says Wallace. "I



Doctors fear that many vulnerable people are slipping through the net

Bethlem, the country's only specialist unit for people suffering from schizophrenia, has an 18-month waiting list. However, she is not calling for more in-patient beds but for a better system of early intervention.

"We need to make sure that

patients do not reach that point. Where things have progressed is that I have a greater chance of making a patient well than in 1986. I also know I can prevent their brother or sister developing the same kinds of problems. But do they always get the optimum

treatment? No. There is just no uniformity around the country in terms of provision of care and psychiatry is demoralised as a result," she says.

SANELINE 0845 767 8000
Noon-2am daily

Tomorrow
"Madness is a happy release from this ghastly situation"

at the end of the line

think self-harm is becoming more violent because there is less help for them," she says. "In the past someone who had overdosed would be kept in hospital for observation. Now the wards are always full and they are sent straight home. There is no refuge now; we are seeing an escalation of hopelessness."

Suicide rates among people with schizophrenia have fallen slightly in the past 15 years, but remain worryingly high. One in ten patients will commit suicide, often in the first few weeks after discharge from hospital.

Some of the hardest calls to handle for SANE's volunteer advisers are from those actually in the process of committing suicide — around ten callers every week. Notes on a call from a 33-year-

old begin: "Sarah has taken 100 paracetamol tablets. She had been sectioned, but came out of hospital on Tuesday. The hospital says it could do no more for her, so she has given up. The GP has said she is past the time for intervention and will probably die... pleased that at least SANELINE cares."

Sometimes a caller has schizophrenia and has delusions, such as being hunted by the IRA or seeing rats run up his legs. He may claim to hear voices urging him to commit strange or violent acts. One successful tactic for controlling voices is to set aside a fixed hour when the voices can have free rein; they can have their say between 6 and 7pm, for instance, and behave for the rest of the day. But some patients do not necessarily want to lose the voices.

Tom, who called recently, "feels lonely — he has lost many friends".

The "classic caller", says Wallace, is a carer, often an elderly mother, living in growing fear of a son aged 30 or 40 who frequently threatens or uses violence: "They suffer from the utter guilt that they are made to feel for having had this child with mental illness. But nobody visits, nobody seems to care — they seem totally excluded and ring here for support."

This is the main theme of calls to SANELINE: the neglect, alienation and despair felt by many of those who phone. Many claim to have been told by their GP that the best way to get treatment is to put their teenage son or daughter

on the street so that they come to the direct attention of hard-pressed mental health services.

SANE was founded as "Schizophrenia: A National Emergency" to campaign for those involved with the "forgotten illness". Mental health is now more a part of public debate — the Government has made it one of its top three health priorities — but there are more cries for help than ever.

SANELINE receives 800 to 1,000 calls a week. It costs £1 million a year to run and funding is tight. "The sad lack of change over 15 years is the desperation of the families." What has not changed is the loneliness and isolation, says Wallace.

Names have been changed to protect identities.

THE TIMES

Appeal for SANE

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reportage

Madness is a release



**MENTAL ILLNESS:
STILL FORGOTTEN?**

Psychiatric wards perform a constant juggling act to find places for people for whom community care is not working. **Penny Wark** spends a day with staff at Homerton Hospital in East London

Dr Martin Deahl could discharge six patients today from his acute psychiatric ward. He won't, because there is nowhere for them to go. Accommodation exists but psychiatric patients need special care and support and putting them in bed and breakfast or in a hostel run by untrained staff does not give them that.

This, says Deahl, a consultant psychiatrist at the Homerton Hospital in East London, is what is fundamentally wrong with the enticing promises made by the Government in the National Service Framework. Of course, mentally ill patients should have 24-hour access to mental-health services. They should have continuity of care and choices. No one disputes that, but without skilled

and appropriate support many of these people can not live safely within the community. They will either harm themselves or someone else. The fundamental problem with mental health services lies not in psychiatric wards but in the lack of provision for mental health patients within the community, Deahl believes.

"The National Service Framework is motherhood and apple pie. All is wonderful, but to what extent it can be delivered is another matter," he says. "It's all very well setting up new teams and initiatives, but when you have not got the basic infrastructure to house people outside hospital it's difficult to see how it will work."

"There is a total lack of supportive accommodation for mental-health patients. A lot have been thrown out of supportive accommodation because they have

broken the rules and they come here because they are roofless. One of our functions is providing shelter for people who have literally got nowhere else to go. We get patients well in hospital, but there is nowhere to send them and, unless they are discharged into an environment where they are supported, they relapse."

Homerton Hospital serves a poor, deprived and multicultural community where social problems pile up on each other and where illegal drugs are easy to obtain. Deahl knows that the moment his patients leave hospital (if not before) they will have access to drugs and alcohol, both of which trigger the return of their illness. Those who come from ethnic minorities — Hackney is home to many asylum-seekers — need even more specific support.

All this is graphically illustrated when Deahl invites *The Times* to watch him work for a day. A gentle middle-aged schizophrenic man has been admitted because he is lonely and his GP feared that he might one day find him hanging. He feels safe in hospital and is charmingly accepting of Deahl's suggestions. But the staff know from experience that he does not always follow their advice outside hospital, and that his thinking is more disordered than it might appear.

On the street he is paranoid about people listening to him and believes that women want to marry him. He will stay in hospital for a few days and be encouraged to accept support when he returns home. If he is to live outside an institution without deteriorating again he will need help with cooking, looking after himself, and he will need friends. He is highly intelligent and proud, but his white T-shirt is dirty.

James is 30 and has just come out of prison for possession of an offensive weapon. He has a history of violence and has broken down again because he followed the instructions of the voices inside his head to stop taking his medication. He has also used heroin, cocaine and cannabis and has special powers, he tells Deahl. He works for the SAS. "That's unusual in Hackney. Who tells you what to do?"

"The pigeons. When they land



The shortage of acute psychiatric beds is often serious because of the lack of intermediate care. Hostels

on a roof I have to burgle that house."

"What do you take?"

"Papers and documents."

"Have the police caught you?"

"No."

Deahl decides to keep him in hospital to assess him — James has the typical symptoms of schizophrenia. "We may decide to in-

ject his medication. We need to link him with a community team and provide carrots in terms of benefits to engage him in a relationship [with a key worker who can support him] and persuade him to take medication."

Jake was diagnosed with bipolar affective disorder three years ago. He was discharged from a hostel in March and has since separated from the mother of his children. He was arrested when wandering around improperly dressed and has been aggressive and suicidal. His medication appears to have been changed since his last admission, possibly by his GP, and despite regular contact with his key worker who is concerned that he is isolating himself. His condition is consistent with drug use, probably crack cocaine.

"Unless you manage to mark someone every day a situation

can go pear-shaped," says Deahl. "Drugs are in everyone's face here, we have people dealing on the wards because our patients are vulnerable and it is one of the main reasons for people being chucked out of hostels. If we followed policy and sent people off the wards for taking illegal drugs we wouldn't have any patients left."

Jake is painfully thin and edgy. Somewhat implausibly he denies that he is a drug user. "I'm very particular as to what I eat. Fruit causes me to be more alert," he insists.

"How have you been spending your time over the last few weeks?"

"A lot of travelling."

Deahl insists that he stays in hospital for a weekend. "I tend to differ," Jake replies. He is asked to return to the ward for two days and will be tested for drugs. "He

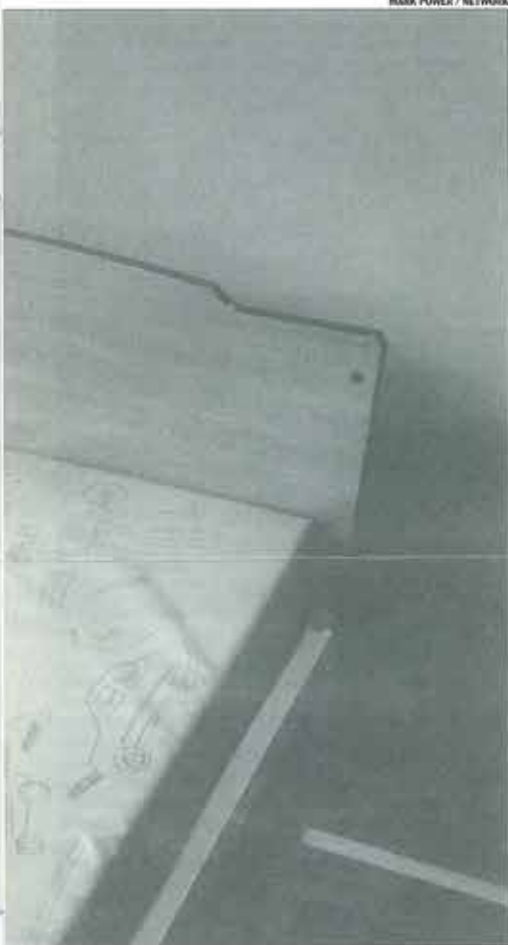
SANE is a national charity set up in 1986 to improve the quality of life for people affected by mental illness. It has three main objectives:

- to raise awareness and respect for people with mental illness and their families, improve education and training, and secure better services
- to initiate and fund research into the causes of serious mental illness through the SANE Prince of Wales International Research Centre
- to provide information and emotional support to those experiencing mental health problems, their families and carers through SANELINE.



from all this

MARK POWER / NETWORK



are not set up for patients who might harm themselves or others

will try to swap his sample," says Deahl. "But if we can get a positive screening we can confront him with it and sit him down and say 'What are you going to do with the rest of your life?' He will probably use drugs here this weekend and get into an argument with the staff."

"A psychiatrist also functions as a social policeman. It is a difficult balance because it's supposed to be a therapeutic relationship but it is also coercive. Few hostel staff are trained in nursing or psychiatry. If someone is unpleasant it is fine for me because I spend very little face-to-face time with them, and the unpleasantness can be diffused among the staff. But if you work in a hostel it is like a family and it has the dynamics of a family."

"People relapse when they are with their families and exactly the same can happen in hostels.

One of the hostels we deal with is half empty but it would not be able to cope with someone like Jake. But the environment in hospital is totally unsuitable for people to stay for a long time."

On the ward today are several alcoholics, several patients who are depressed, an anorexic girl, a manic patient who is also sex-

'The hospital environment is totally unsuitable for people to stay for a long time'



Dr Martin Deahl: "There is not the infrastructure to house people"

ually disinhibited and who holds Deahl's hand as though he is her closest friend, and others who are frightened and anxious about approaches from the opposite sex.

There is a young Muslim man whose upper body sways backwards and forwards. His speech is slurred and his medication needs adjustment. He also needs help to prepare him to live alone, and support to ensure that he does not resort to taking illegal drugs and drinking alcohol.

There is a Kurdish political refugee from Turkey who has attempted suicide three times in three months. Four days ago a neighbour found him with a rope around his neck. As a child of three he was forced to watch a woman being raped by soldiers; he has also been tortured.

He has been in the UK for five years but speaks no English and, even with a translator, conversation is stilted and difficult. Working out how to treat him will rely on nurses' observations. Altogether there are 29 patients in a ward that has only 18 beds.

"The more proactive we are in the community the more illness you detect and the more you increase the need for beds," says Deahl. "Sometimes we need to send people to private beds but this is not a solution because there is no continuity of care. They are often miles away from their life and families."

Jessie, 47, admitted a month ago with psychotic depression, is willing to give up her bed. Anx-

ious and determined, in fact, and she tries to trade on Deahl's need for beds. "I know there is a bed shortage and I am bored out of my mind here," she says. Deahl, certain that she is more fragile than she realises, allows her to leave the hospital for four hours. Jessie is disappointed and angry. "It's vicious and evil," she shouts as she leaves.

People are supposed to go on leave because it is appropriate for them," says Deahl. "But when you have got a bed manager breathing down your neck there are times when we need to let them go. I have had a 13-year-old girl on the ward. It should not happen but it does. Often we look after people inappropriately because no one else will. And sometimes you wonder why you treat people because madness is a release from a ghastly situation."

"It is true that there are more beds than there were ten years ago, but they are in the forensic services, in so-called medium-secure services (and in the private sector).

"They are well-run services but the sad thing is that you may have to kill someone to get access to these highly expensive institutions. If you invested more money in the basic services you might stop some people offending."

SANELINE 0845 767 8000
Noon-2am daily

Happy 10th Anniversary SANELINE!



Helen Hyslop, SANE's Director of Operations, explains the vision behind SANELINE.

This year our national helpline, SANELINE, celebrates 10 years of providing help and support. It started with the vision of linking people with mental health problems to expert counselling and advice, information and ongoing emotional support. Mental health problems can have a devastating effect on people's lives, leaving them feeling alone, isolated and desperate.

SANELINE is the only national helpline for all mental health problems, staffed 365 days a year by 250 dedicated volunteers until 2am. The helpline provides support and advice to anyone suffering from mental health problems, their families, carers and friends. People struggling with mental health problems often find it difficult to get accurate information about symptoms, treatments and services. SANE believes that immediate, one-stop access to reliable information can relieve some of the mystery and anxiety, and therefore make it easier to cope. SANELINE volunteers are trained to offer support and reassurance during times of crisis, while also giving information to enable callers to make informed decisions.

The volunteers have the backup of the SANELINE Information Database (SID) which is the most comprehensive source of mental health information and local and national mental health services in the UK, containing over 16,000 records on statutory, voluntary and independent mental health services.

Ten years on we continue to develop the service, and our Caller Care scheme offers call-backs to our more vulnerable callers. As one caller said: "Even if I'm too depressed to answer, I know that it's SANELINE ringing at the time they promised and that makes me able to live through another day."

SANELINE is a valuable resource and provides important support for anyone worried about mental health problems. SANELINE is open from 12noon to 2am, 365 days a year on 0845 767 8000. Calls are charged at local rate.

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The Admit Charitable Trust, Amicus-AEQU Learning Fund, The Albert Hunt Trust, Amhurst Brown Colomboth, Barclays PLC, Bridge House Estates Trust Fund, City Parochial Foundation, Community Fund, The David & Frederick Barclay Foundation, The Denman Charitable Trust, The Diana Memorial Trust, The Dining Charitable Trust, The Ditchman Charitable Trust, Donald Fvresaker Trust, Fischer Francis Watts & Trees, Garfield Weston Foundation, Godfrey Holmes Foundation, Granada Sky Broadcasting, The HB Allen Charitable Trust, The Henry Smith Charity, The Highbury Charitable Trust, The Kathleen Hanbury Memorial Charity, Lark Trust, Lloyds TSB Foundation for England & Wales, Mr & Mrs JA Pye's Charitable Settlement, Pfizer Pharmaceuticals Group, The Philanthropic Trust, The Robert Gavron Charitable Trust, Rothschild Trust Corporation Limited, The SMB Charitable Trust, The Sobell Foundation, The Towry Law Charitable Trust, Vodafone Group Charitable Trust.

sane report

It is midnight on a stuffy Friday evening and I am walking in Lincoln's Inn Fields with Mick Carroll, Head of Quality and Information for St Mungo's charity. Following a series of campaigns, the government spent an initial £30 million, rising to a current budget of almost £200 million for the three years from 1999/2000, to protect the public from the sight of human beings left to decompose in shop doorways. In London alone there were around 1,000 people sleeping rough each night, 60 per cent reckoned to be mentally ill, many former patients decanted from the closing hospitals. Now there are around 300 people on the London streets.

"There are different groups of homeless now" says Mick Carroll. "There are still those who rotate between the streets, prisons and hostels, but there are other groups who colonise the streets and beg." As in all other areas of life, there is the huge increase in the number of people taking illegal drugs. "82% of the residents at the Endell Street hostel use intravenous heroin or crack cocaine, which is so cheap that it has almost replaced alcohol" says Carroll.

But with the infusion of government monies and the impressive organization of outreach teams, such as the Contact and Assessment Team (CAT) for which Luton Sinfeld is Group Manager, it is more difficult to disappear from services. The 'Soup Run', which I filmed over 20 years ago when it was a new concept, continues funded by competing charities. In the past couple of years, providers have been persuaded to co-operate and reduce services to a more

Back on the Streets

To discover how things have changed in the last 15 years, **Marjorie Wallace** revisits some of the most disadvantaged areas where mental illness among the homeless continues to present real problems.

sensible level. I was amused to see the soup and sandwiches being delivered literally from door to doorstep to regular inhabitants of cardboard boxes - an outreach form of Room Service.

For mentally ill people, the street in the past could offer more stimulus than a lonely room. New hostels with more flexible rules built from funds from the Homeless Mentally Ill Initiative and now the Rough Sleepers Initiative provide an albeit often temporary alternative. Opposite the glass palace of the ITN building where I worked for so many years, there is a new purpose built hostel for homeless mentally ill people. Gary Thomas, the project worker, is looking after 15 residents who stay on average 18 months before being moved to other St Mungo's projects. The place is homely and colourful. Instead of the usual dirty grizzly dishevelled décor of hostels I have previously visited, the walls are painted in warm vibrant colours with uplighters and side lamps. Everyone has their own room which they can decorate as they wish, and each has a desk and basin. A landscaped, floodlit courtyard with a table tennis table gives it an air of luxury many hostels further up in Kings

Cross would envy. The mental health team, FOCUS, refers residents found by outreach teams sleeping rough and mostly diagnosed as having schizophrenia. Duty doctors and mental health workers can be called. Not, according to Gary, that there is much need for a crisis intervention: "Most people stabilize here, and we get used to their behavioural patterns" he says. "We leave our office door open. There is a computer where they can access the Internet, and they can come and go as they wish."

It is difficult to see how such shattered people can be put together again

Neil, aged 27, sits on the floor in the lobby. His eyes have a disconnected look, but he turns and responds with a delightful smile. At the age of 19, he says,

his mother threw him out of the house because he would not work, and for the next 8 years he roamed the country, sleeping rough in fields, stations, alleyways, preoccupied with disturbing thoughts and voices in his head. Three months ago an outreach worker found him sleeping rough in London, and took him to the hostel. He takes medication for his illness (Risperdal) and is beginning to think of going to college and taking up photography (there is a lecture on this tomorrow morning). "I haven't any family" he says "but I'm beginning to feel more confident."

In the living room, Leandro de Silva relaxes in front of the television. He came from Portugal 11 years ago working at first in kitchens, but when he couldn't concentrate and heard voices, he was sacked. From then on he slept rough and recently was taken into Homerton Hospital in East London. He doesn't mind his medication, which he thinks makes him feel better, but he has no ambition to go beyond the safety of the lounge.

Not all the hostels are as pleasant. A volatile group of drunk and drugged men sit on the doorsteps of a hostel in

Southampton Row which accepts people whatever their problems (and if necessary, their dogs). Inside, a few figures stagger clutching 'cola' bottles and steadying themselves against dilapidated walls. Attempts have been made to cover the cracks with schoolroom-like paintings from residents and workers and cheerful messages about activities, but the dereliction, both physical and emotional, seeps through. It is difficult to see how such shattered people can be put together again.

The government has met its target of reducing the numbers of those sleeping rough by two thirds by 2002. But the need is not for rolling or short-term shelters - the 'Big Street Winter Party', as it is known to workers - nor hostels where people are moved on. The concern is that just as unsavoury bed and breakfasts absorbed the most difficult psychiatric patients, the visible neglect of people on the streets will be made invisible again, hidden in substandard lodgings or flats on council estates where the mentally fragile make easy targets for drug dealers and other criminals.

Margaret Edwards, SANE's Head of Strategy, comments:

"The efforts to help rough sleepers have given many people the chance to make a new life. As SANE's return to the London streets shows, hostels can now offer a pleasant environment, providing not only a roof but structure, occupation and motivation to improve physical and mental health. With the CAT teams and attached health workers, they may provide the first real treatment and care some people have had."

Now that the rough sleeping target has been met, the same effort and urgency must be put into providing a proper framework for those with enduring needs

However, such hostels are usually temporary, providing support for limited periods of time. There may be an expectation that, with intensive support, people with mental health and other problems will 'get better' and be able to cope on their own when their time in a hostel comes to an end. This may be possible for some, but



Simon and Margaret Morton in 1968.

A Broken Dawn - The Story of

I will never forget the memory of my first visit to the neat house on an... Margaret Morton lived with her son, Simon says **Marjorie Wallace**.

Margaret and I sat for hours downstairs in her room which was lined with clocks from all over the world, chiming away the hours she would spend listening to the steps of Simon upstairs, terrified that he would walk over to the bathroom and take yet another overdose of pills. She was told she did not have the right to prevent him, Simon, who despite his 27 years had the golden looks of a choirboy, had been a high-flyer who had won some literary awards. He had become withdrawn, frightened and aggressive, and finally so ill

that he had to spend many years in and out of hospitals, hostels and a flat in the community to which he attempted to set fire.

Margaret, according to the philosophy of the time, was told there was nothing that she could do to save herself from his threatening visits, but to move house and conceal her identity. Simon, however, searched for her, recognised an ornament from their old house in the window of her new living room, and from then on their years of mutual imprisonment began. "It was as though he had taken me hostage," says Margaret. "I never dared leave the house because I

knew when I returned he might have taken another overdose. He couldn't sleep at nights and if I didn't lock the door he would come and bang me about the head, telling me I was the Devil. He was taken to hospital and pumped out so many times, but they just sent him home afterwards with the money for his bus fare." It was unbearable to imagine the loneliness of this young man who, too afraid to go out, would sit in his room, like a punished child, curtains drawn, listening to the doors of cars slamming as other people went out, leaving him with his voices, poems and dreams.

Three years ago Margaret, in her late 70's, moved to a cottage in Oxfordshire. Simon, aged 41, continued his solitary existence in his new bedroom, but then relapsed and was admitted to St Crispin psychiatric hospital. He hit a nurse there, was discharged to a group home, smashed a window, returned to the acute ward, but was discharged again to wander the streets. He is now in accommodation with Shelter. Simon is artistic and has sold a few paintings, and his mother published his poems in a book 'Whispered Words' to "get enough money to pay for an outing for him". She is pessimistic and has seen

ANDREW BURMAN



Terry Hammond



SANE would like to thank Terry Hammond for his ongoing support. It was Terry who first suggested in 1982 that Marjorie Wallace should come down to Southampton and Portsmouth, where he was working as an officer with the Stenham Housing Association, and see for herself the appalling conditions into which people with mental illness were being discharged from the rapidly closing hospitals and left to enjoy their new 'independence'. Terry is now Membership Officer for the National Schizophrenia Fellowship.

many will have long term needs, recognised by the government in its funding for permanent accommodation for rough sleepers with mental health problems.

Before the drive to take people off the streets, people with mental health and other problems could be discharged from

hospital to a hostel. With money now ring-fenced to tackle street homelessness, this is a fast diminishing option. Yet these are the same people who are likely to have most difficulty in making a life in the community.

Now that the rough sleeping target has been met, the same

effort and urgency must be put into providing a proper framework for those with enduring needs. Without this, people with serious mental illness and other problems will 'be made invisible again', left isolated and vulnerable to the very street pressures from which they need protection and help."

Marjorie Wallace chats with a resident of St. Mungo's Hostel. "I haven't any family, but I'm beginning to feel more confident."

Simon Morton

tate near Fordingbridge, where Ella

little of the promised help for families like her. "I had an understanding GP in Fordingbridge, and there was a kind person from the social services who took us both out at the weekend occasionally. The police were quite kind too, but they said he was sick and it was the job of the hospital." She feels her campaigning for the recognition of schizophrenia has never got very far.

Simon still doesn't see himself as being ill. Does he come to visit her now? "Oh, I don't give him my telephone number... I wouldn't like him to visit because he might get back into one of his tempers,

and I'd get my head banged. I'm getting too old. I always thought that he'd have a better life, but that doesn't seem to have happened. He used to be crying and unhappy, and now he just accepts things, which is even sadder. I doubt when I die if anyone will fight for him. They don't have much patience with schizophrenia, do they?" Simon may be more optimistic: as he writes in one of his poems:

"In the midst of life
New Life is born
There is always hope
In a broken dawn"

John: Nowhere Man

I first met John Barrett eleven years ago, while making a film about homeless mentally ill people in London. He was sitting in the doorway of a building in Kingsway, his bed and few possessions around him. Beneath his dishevelled appearance I could detect the chiselled features of a fading icon. "I should have gone into the church," he told me "but I was put off by a priest, then I got ill, and the doctors said it was schizophrenia." He started a teacher training course but had to give up and from then on his life was a series of hospitals, medications that gave him the shakes, and when he could not live at home - life on the streets. "It's the Black Death of this age," he says dramatically. "We are the forgotten men."

Following the film John's mother, Joan, who had lived through nine months of anguish without news of her missing son,

saw the programme and recognised him. She rang me and asked if I could find him again. The following night I spent amongst John's former colleagues on the street, and was eventually told where to find him. His religious delusions were overtaking him now and it was clear he needed help.

"I used to attempt suicide but I don't allow things to get to me so much"

He was taken into hospital and now lives with four other 'cronies' - he is careful in his use of the word 'friend' - in a house where they cater for themselves or each other. "I live quite a comfortable life," he smiles. "I used to

attempt suicide, but I don't allow things to get to me so much. The State looks after me and gives me £75.50 per week and I pay £13 in rent. I smoke a lot and drink a little, but don't gamble any more and I never want to return to the streets, except when I'm broke and go back to get some sandwiches and soup."

Today is a poignant occasion. John is celebrating his 60th birthday with his mother who, now in her late 70s, has moved to a sheltered flat for widows. "It's a sad life for both of us," she says. "I have one son who has everything, and John who has nothing, but it's much better than it used to be. At least I don't have to worry about where he is." John is more reconciled to what he regards as his wasted life. "You must generously accept your interior darkness," he quotes "you get used to belonging nowhere".

sane report

In April 1998, Christopher Moffatt, a young man of 27 diagnosed with paranoid schizophrenia, killed retired civil servant Anthony Harrison and severely injured his wife Jennifer. In December 1998, Christopher committed suicide in Broadmoor Hospital.

In July 2001, an independent inquiry reported on the care and treatment of Christopher and two other psychiatric patients who committed homicide having been in the care of mental health services in Hampshire - Mark Longman, aged 26 at the time, who killed his father Kenneth Longman in June 1996, and Paul Huntingford, aged 56 at the time, who attempted to exorcise his mother Lena Huntingford, resulting in her death in December 1997.

Christopher Moffatt was a bright child, doing well at school and gaining a university place. Between school and university, his family became concerned at his cannabis use and consulted their GP. In 1993, a consultant psychiatrist thought Christopher had a severe psychosis, with voices telling him that he was Jesus Christ. In 1994, Christopher was admitted to Park Prewett Hospital in Basingstoke but continued to use illegal drugs during periods of leave and suffered a depressive illness and return of his psychosis. He was discharged in November 1994 but did not feel ready, telling his mother: "The problem is in my soul. I believe that I killed God and I killed myself. I think they are letting me out quite early. I've tried and tried to get better. I still feel suicidal."

In early 1995, Christopher stopped his medication and, although he restarted it, was not managing. Not ill enough for a staffed hostel, he was placed with two other mentally ill people in a top floor flat, which at night became a haven for addicts and gangs. He was then offered bed and breakfast accommodation for homeless men, but went to live with

Homicide Inquiries:

The Roll Call of Unnecessary Tragedies

Marjorie Wallace examines the heartbreaking story of Christopher Moffatt and highlights the shocking statistics revealed by an analysis of 69 inquiries into homicides committed by people in contact with mental health services.

his family for a year. He still believed he was the Messiah, and following another spell in a community house, he was readmitted to Parklands Hospital as a detained patient. He absconded from hospital on the day of his admission, and on four more occasions before he was transferred to Burnham secure psychiatric unit at West Park Hospital in Epsom in August 1997. During these absences, he broke into a house where he was found by police, and spoke more than once about homicidal thoughts.

In the Burnham secure unit, Christopher made progress with medication and therapy but despite requests from his family for him to stay in secure structured care, he was transferred back to Parklands Hospital in November 1997, still only partially compliant with his medication and with no insight into the extent of his illness and the need for treatment. In February 1998, he again absconded, having been allowed 30 minutes unescorted leave in the hospital grounds. The police officer who led the search said: "We knew that he might stop his medication and be a risk to himself, but we had been given no information whatsoever about his

previous homicidal thoughts or the severity of his illness". During Christopher's seven-week absence, his family informed his key workers that he was likely to be living within 30 miles of the hospital, but no other mental health teams in the area were alerted. He remained undetected until the day he killed Anthony Harrison.

In December 1998, Christopher was convicted of manslaughter on the grounds of diminished responsibility and sent to Broadmoor Hospital where he had been held on remand. Although his family felt he was beginning to respond to treatment in Broadmoor, Christopher was remorseful and still hearing voices. Within two weeks of his sentence, he hanged himself with his shoelaces.

The July 2001 report into the psychiatric care of Christopher, Mark Longman and Paul Huntingford is one of the most powerful indictments yet of the belief that everyone, however disturbed, can be adequately treated in the community. It puts a huge question mark over the policy and the way in which it has been interpreted - that everyone should be able to be in the community or in

small acute units which were never designed for long term care. It is not the fault of any one person but of a system which does not, and without huge investment cannot, protect desperately ill patients, their families and the public.

Homicide Inquiries

Since 1994, the NHS has been required to hold an inquiry when a person in contact with mental health services has committed homicide.

There is a widespread view that inquiries create a culture of blame which damages morale among hard-pressed professionals, waste valuable time and resources, and increase the stigma for the vast majority of mentally ill people who are never violent. What is the purpose, critics say, of pointing the finger of blame at individuals and authorities at such public cost, when these reports simply repeat again and again the same findings and identical flaws? It could also be argued

that making the reports public breaches confidentiality and disturbs the delicate relationships between patients and professionals.

The government has announced that it intends to replace the current system of inquiries commissioned by health authorities with investigations commissioned by the Department of Health or by the Commission for Health Improvement. In some ways this could be said to be welcome because of the concerns about the culture of blame, and because there is no evidence that homicides by people with mental illness are increasing. But the government's proposals will not ensure that critical findings will be made public, and cases be examined, which could provide lessons for the future.

The current inquiries allow a "finger-tip" search of the factors leading to a tragedy, without which we would never know properly what was happening on the ground. To get at the reasons behind what happened, we need to look at the whole picture, at the interactions between the individuals, their families and the services. As in any detective story, it is the tiny things - both obvious and obscure - which

can be critical clues.

It is the detail which can reveal how services are being undermined by organisational and administrative flaws such as the failure to keep proper records or to exchange critical information with other agencies. No-one wants to blame individual health care professionals, and the inquiry reports show in what difficult circumstances and with what commitment many are working. But we must be able to see what triggers human error when it occurs, to prevent similar triggers in the future. If professionals are so overburdened by paperwork that they have no time to talk to their patients or provide a proper level of care, then that needs to be looked at for the sake of the professionals themselves and their patients.

The other dimension which the current inquiries allow is the voice of the families and victims. I have personally attended the publication of around 30 inquiry reports, having already known or met many of the families, and I have been appalled at how neglected the victims' families have been in the whole process of understanding what led to their loss, let alone at the fragility and isolation of the families of the perpetrators of the tragedy. So often, families on all sides are excluded - at one inquiry briefing, the victim's family arrived to make a statement, although they said they had not been given the address.

Yet in almost every case, families and victims have shown remarkable compassion. For example, Jennifer Harrison wrote to Christopher's mother after Christopher committed suicide, expressing shock and sorrow at the death of a son: "Our hearts go out to you. ... That such a sick and vulnerable young man should be so frequently let down by our mental health services beggars belief."

SANE therefore believes that while inquiries may be streamlined to be less expensive and delayed, they provide essential evidence to



Robert and Gillian Bayley.

New Developments in M

Robert Bayley, artist, writer and musician, believes that his life was transformed by the new medication Clozapine. Here he puts forward his case for the usage of atypical neuroleptic drugs such as Clozapine.

Imagine an illness that ravages the brain and leaves the sufferer in a state of desperate isolation. A neurological disease that attacks the inner psyche, causes unrelenting persecutory voices and visual hallucinations and brings with it torment and crippling despair. This illness is called Schizophrenia, and is often misunderstood by society as a whole. Those who suffer from it are often left to fester, neglected

and alone with little in the way of compassion or sanctuary. So, with many medicinal advances in the world today, what treatments are available? I have lived with the diagnosis of paranoid schizophrenia for most of my life, and my experience of medicinal therapies is mixed. At the commencement of treatment I was prescribed what are now regarded as the 'old school' anti-psychotics, such as Chlorpromazine, Stelazine or

Pimozide, which were taken orally. I was also prescribed depot injections, such as Depixol and Moderate, which are injected into the body, and slowly release into the bloodstream, and are often used for patients who are non-compliant with taking medication regularly.

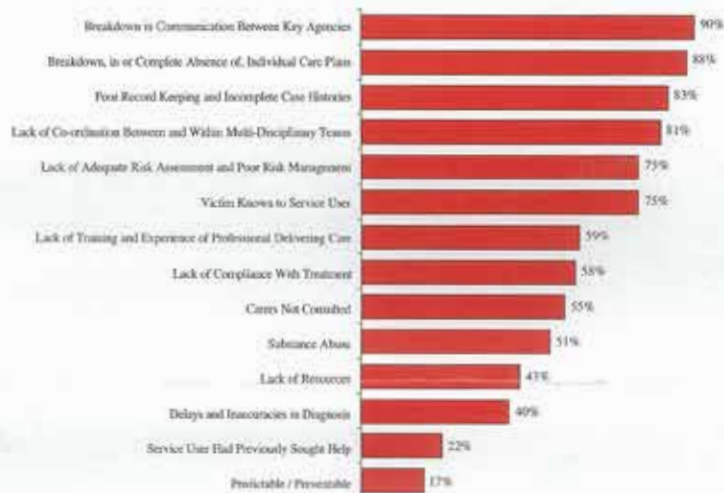
I endured this method of treatment for many years, and had to live with a profusion of side effects that seemed to spiral out of my control. My psychomotor functioning was

severely affected, causing severe shaking, a curious padding motion when supposedly stationary, loss of control of my limbs and hands, and a general sensation that I was not in charge of my own body. Internally my thought processes were markedly affected, to the point that I could not think with any clarity and everything seemed dull and disconnected. I felt like a zombie, whose mind had been treated with substances that stripped away my



Christopher Moffat (left) was a gentle boy who descended into paranoid schizophrenia. After killing a man at random, he killed himself. Both tragedies could have been avoided.

Areas of Failure as Reported in 69 Homicide Inquiries



shape future policy. They are the "black box" which allows us to see what has gone wrong. Just as it would be negligent to ignore the findings from an air or rail crash just because millions of other people

travel safely, so it is wrong not to confront the failures and lessons from mental health tragedies.

SANE has analysed 69 inquiries into homicides committed by people in contact with mental health services

(all but four of the inquiries reporting during the period). The first part analysed 33 inquiries reporting between 1994 and 1998 (the events taking place between August 1992 and October 1997), the second 36

inquiries reporting between 1999 and March 2001 (the homicides occurring between June 1995 and March 1999). Through an analysis of the conclusions and recommendations of the inquiry

reports against thirteen key factors, SANE has been able to identify key failures leading to each tragedy, and compare findings in the two parts of the analysis. Both parts reveal the following failures:

- In 53% of the cases there was a multiple failure of care through simultaneous breakdown of five major aspects of care: poor communication at all levels; inadequate or non-existent care plans; poor or non-existent record keeping and inadequate case histories; lack of risk assessment and poor risk management; and poor multi-disciplinary team work.
- In 22% of the cases (15 out of 69) ten or more of the thirteen key factors against which the analysis was made were selected for criticism by the inquiry teams, indicating a massive breakdown of services in both hospital and community.
- In about one in six cases, the inquiry team regarded the tragedy as predictable or preventable. In all of these, the report highlighted lack of proper risk assessment or an inadequate care plan.
- In almost one in five cases, the service user had sought help with unsatisfactory results, and in almost half, carers' direct concerns about the individual's safety had not been taken seriously.
- Comparing the two parts of the analysis, poor multi-disciplinary team working, poor record keeping, and difficulties with diagnosis all showed an increase over the later period.
- The later analysis also showed an increase in non-compliance with medication and substance abuse as factors in the tragedy.

The second part of the analysis looked at additional factors including issues of confidentiality,

Homicides by people with mental illness do not usually result from chance, but from a series of failures to look after a person

missed appointments and comment on internal inquiries. A disturbing finding was that 36% of the inquiries reporting between 1999 and March 2001 were critical of the way in which a previous internal inquiry had been conducted.

Given the number of inquiries that have now taken place, and the similarity of the findings and recommendations in so many of them, why is SANE so sure that they should continue? Although the inquiry teams are less and less inclined to judge that the homicide was predictable or preventable, the 5-year report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness published in March 2001 judged that over two hundred suicides a year by people with mental illness are preventable. Close reading of the inquiry reports would suggest that the warning signs for those tragedies were equally present, and that had they been acted upon, there would have been less damage to everyone concerned.

Homicides by people with mental illness do not usually result from chance, but from a series of failures to look after a person, and often to protect a vulnerable family. SANE believes that, although not all homicides by mentally ill people can be prevented, many more than at present could be predicted or prevented if the proper care were provided when it was needed. Dimming the searchlight on care such as that revealed in the Hampshire inquiry would do a grave disservice to everyone affected by mental illness, their families and the public.

Education Give Hope for the Future

intellect and destroyed my creativity. All I wanted to do was sleep, only exacerbating the lack of motivation that the original illness can itself cause. And sleep I did, spending most of my day in bed, achieving little, so reinforcing the sense that I was capable of nothing that was tangible, my self-esteem sinking to new depths. But there was worse to come, an aspect that would bring fear and trepidation.

It came in the form of something called tardive dyskinesia. I noticed that I was beginning to experience a strange involuntary rippling around my mouth and tongue, which then spread to my limbs. I found this to be socially embarrassing, as my tongue would thrust and roll, without my having control over it.

This side effect became increasingly debilitating, and when acute is often confused as being symptomatic of the original illness that these medicines were supposed to be treating. But this was taken into another sphere of terror when my tongue began to expand to the extent that I felt akin to a dog that was panting after a period of intense exercise. Slowly, as the tongue continued to grow in size, my oesophagus began to constrict, my fear being that I would gradually become asphyxiated. It was only through the rapid ingestion of side effect medication that I feel that my life was saved. Just the memory of that incident sends shivers down my spine. Tardive dyskinesia can be irreversible after prolonged periods

of taking these medications, and that in itself should be warning enough that their usage is inappropriate and severely debilitating.

Since 1993 however, I have been treated at the Maudsley Hospital in London with the drug Clozapine, one of the new range of atypical neuroleptics. Since I began taking this medication my quality of life has improved in many areas. I can now exist on a higher creative level, absorbing the intellectual and emotive aspects of music, literature and art. My outlook is more positive and I am able to think with an increased clarity. I am now in control of my body and its movements, and so socially I feel

more confident. A lot of this is attributed to the fact that the medicine itself works with a higher level of precision, so not affecting the areas of the brain that cause the wide ranging myriad of side effects that I have previously described.

I can now exist on a higher creative level

There are of course some side effects, some not so pleasant, but in comparison they are much easier to live with. The most serious problem with Clozapine however, is that it can cause a decrease in the white blood cell count, so causing a breakdown

of the immune system. For that reason, the patient's blood must be tested before a new prescription is dispensed, so for some people the drug is not suitable. There are other options such as Olanzapine, which is made up of a similar compound, but removes this particular risk. In terms of cost these treatments are not cheap, particularly with Clozapine, as the testing of the blood of every patient has to be absorbed, but their efficacy is undeniable. Surely there should not be a price on achieving some relative quality of life?

They are not a cure for this destructive and relentless disorder, for that has yet to be found, but they provide the patient with a certain sustenance with which to battle against the elements of a terrifying

illness. That is where their strength lies, for they allow expression, they remove the risk of tardive dyskinesia, and take the edge off the more troublesome aspects.

My wife, who is also my carer, opines that the illness is still most evident in terms of the voices, visions and disturbances. However she no longer needs to lock me in our home for my own protection. Before this treatment I would disappear, on wild excursions, living on the edge of life itself. I would exist for days with no sleep, testing all around me, my mind crashing down into hopeless oblivion. Today, I still suffer, at times to a great degree, but I do not have to battle with the side effects that almost destroyed me, and now I am free to create, to fight back.

sane report

The National Service Framework for Mental Health promises the right bed, in the right place, at the right time; and a place of safety in times of crisis. For the first time carers will be given information about the medications, therapies and care plans of the people they are looking after, and given care plans themselves. The government's proposals for a new Mental Health Act end the outdated polarisation between hospital and community, reflecting reforms SANE pioneered in our Balance of Rights campaign.

Yet currently, one in three people who seek help are turned away from services. Many of the thousand people a week who call SANELINE give graphic evidence of this with individuals, families and carers often feeling there is nowhere to turn. If a person who is ill fails to keep an appointment or appears not to co-operate with the system, they are all too easily allowed to lose contact.

In the last twenty years, 50,000 psychiatric beds have been lost. Acute in-patient wards in every big city are grossly overcrowded, with occupancy rates running frequently between 110% and 120%, against a recommended rate of 87%. The number of patients who have to be compulsorily detained in hospital has trebled since 1980, and in some places only patients referred from the courts or under a section of the

SANE's Vision for the Future



Margaret Edwards, SANE's Head of Strategy, discusses the future of mental health services and outlines SANE's priorities for care and resources.

Mental Health Act secure a bed. In the last ten years there has been a nine-fold increase in private psychiatric care, often requiring patients to be treated far away from home.

For families and carers, premature discharge from hospital because of pressure on beds, or inability to obtain a bed, mean unsupported home care. For professionals, there is the constant dilemma of whether to discharge someone who is still acutely disturbed or turn away another patient who may be just as much at risk.

With the loss of beds through closure of the old psychiatric hospitals, and the failure to replace them with sufficient nursed beds and supported housing, we lost the backup of a place to go when a person is no longer able to cope on their own or living with their family. We have also lost the concept of asylum; a place of refuge that rec-

ognizes that people at some points in their lives and in their illness may need time and space away from the multiple stresses they feel.

Assessment, care and treatment must be given legally binding reality, with sanctions on services which fail to provide them. Where rights cannot be included in the new Mental Health Act itself, they should be reflected in good practice guidelines in a Code of Practice with teeth.

To encourage people to use services voluntarily, we need to improve in-patient and out-patient facilities and provide new, more targeted medication with other therapies. We need:

- more psychiatric beds and twenty-four hour nursed units in small, modern centres of excellence able to provide assessment, diagnosis and high quality care in a therapeutic environment;
- recruitment and training of

mental health professionals in sufficient numbers to allow manageable caseloads and acceptable bed occupancy levels;

- accommodation in the community staffed by trained and experienced mental health professionals able to provide risk assessment, care and supervision, if necessary on a twenty-four hour basis;
- national standards in training and risk assessment.

Resources need to be backed by recognition that acute mental illness needs to be taken seriously at all times. Everyone concerned - the patient, the family or carer, and the professional - has to be aware of the possible manifestations of acute mental illness, of the potential need for more intensive treatment and

support, and the possibility of relapse. Families and carers need to be taken into the confidence of the person for whom they are caring, so that they are not caught in a lonely circle of ignorance.

Nearly one-fifth of the calls to SANELINE are from families and carers. A recent survey of carers calling the helpline showed that the need for information was the main reason for calling, and that carers are three times more likely to contact SANELINE for information than service users. The majority of those included in the survey were already in contact with services, and a large proportion of those for whom they were caring had seen a mental health professional within the month preceding the call.

A survey of 10,359 people who contacted SANELINE between January 1996 and June 1998 reporting a history of mental illness and suicidal intentions showed that half

of the callers had attempted suicide in the past, and almost one-fifth were planning it at the time of the call. The survey showed that more than three-quarters of the suicidal callers had been in contact with a health professional in the month preceding the call. SANE has called for an initiative to give more intensive support to people at the critical time when they are on leave from or have just been discharged from hospital.

SANE welcomes the new reforms and resources being put into mental health services, but it is essential that the new measures target not only the politically visible minority but provide a revolution in health care for all. The danger is that the new measures will tackle the tip of the iceberg at the expense of the one in ten who seeks psychiatric help, leaving the less vocal to suffer in silence.

Access to care and treatment must be available for everyone. We need a gold standard of mental health care, where no patient is discharged from care without a risk assessment and care plan, and there are enough beds and other facilities to ensure places of asylum in the true sense of the word.

We need a victory for common sense and compassion over outdated ideologies and insensitive bureaucracy. Only then can we reduce stigma and restore confidence that an adequate level and quality of care will be available for all who need it, when they need it.

Knowledge Heals

Only through research can those with schizophrenia and depression expect a cure, or at least much improved treatments.

Mental illness is one of the most neglected areas of medicine and as a consequence has been overlooked in the field of medical research. For this reason SANE has raised over £6 million to establish the Prince of Wales International Research Centre for Schizophrenia and Depression in Oxford. For the past five years cutting edge research has been carried out by the internationally renowned scientist, Professor Timothy Crow, who heads up a fifteen-strong team of scientists in his role as SANE's Honorary Scientific Director, working with twenty

research centres worldwide. Thanks to the enormous generosity of Matti and Nicholas Egea, HM King Fahd, HM The Sultan of Brunei, and with grants from the Medical Research Council and Oxford University, the Centre is now nearing completion. It is expected that the building will be occupied by April, and a formal launch is planned for later in the year.

The overall aim of the research programme is to determine the nature and causation of psychosis (in schizophrenia and manic-depression) with a view to devising new treatments. Professor Crow's achievements include pioneering studies of the

anatomy of the brains of people with schizophrenia, and studies to demonstrate that the usual asymmetry in the development of the human brain is less pronounced in schizophrenia. This has led to the fascinating proposal that schizophrenia might be due to a fault in the development of an area known as the "language centre", a finding which could unlock the door to discovering more about this disease.

Aims of SANE's Prince of Wales International Research Centre

- to establish the causes of and better treatments for schizophrenia and manic depression
- to become an international forum for discussion in this field
- to disseminate education, awareness and information on mental illnesses to scientists and the public

The striking new building, designed by award-winning architect Demetri Porphyrios, will enhance the already established reputation of the Centre as an example of excellence and innovation within the field of mental



health research. We are planning to expand the research streams to cover biological, social and epidemiological research and other activities to fulfil the original vision of the Centre as a flagship of hope for those suffering from severe mental illness, their fam-

ilies and the public. We will run seminars and provide an information service to reflect our motto: "Knowledge Heals". More detailed information about the research programmes is available online at www.psychiatry.ox.ac.uk/powic/index.html

SANE's Prince of Wales International Research Centre

SANE relies on voluntary donations

To make a donation to SANE call 020 7422 5544 or email fundraising@sane.org.uk

