

The Forgotten Illness (II)

● Mental illness affects one family in 10. It is three times as common as cancer and can be just as devastating.

● Schizophrenia, alone, affects one in 100 people – at least 55 million world-wide. The numbers are staggering and so is the stigma surrounding it.

● In 1985 *The Times* ran a series of articles which led to the foundation of SANE. Many people found reprints of the first series useful, and asked for this further collection to mark steps in SANE's continuing campaign for awareness and understanding of serious mental illness.



This woman is suffering from schizophrenia. She spends her days lying in bed in a hostel for homeless women, listening to the “voices” which fill her head. They terrify her with their insistent criticism and demands. Her life was once full of promise. Now, aged 25, it is shattered. There is no end to her mental agony, no cure for her illness. Her neglect is called “care in the community”. Medicines, if she could be persuaded to take them would reduce some of her symptoms. But unless she gets proper treatment for her illness, and until research brings better understanding of schizophrenia, people like her will continue to suffer.

Photograph by SNOWDON



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A SANE PUBLICATION

The forgotten illness lingers on



The forgotten illness

ON DECEMBER 16, 1985, *The Times* launched a campaign on schizophrenia entitled "The Forgotten illness". It had three aims: to sweep away the secrecy associated with schizophrenia, to stimulate research into the disease, and to stem the disaster about to hit the country after the 1983 Mental Health Act which sought to minimise institutionalised care and to discharge the mentally ill into "community care".

The campaign provoked thousands of readers' letters showing the extent of the illness and the suffering it caused to families of schizophrenics as well as schizophrenia sufferers themselves. The writer of the series, Marjorie Wallace, was made Campaigning Journalist of the Year for her "outstanding series of articles", and the campaign led to the formation, in 1986, of Schizophrenia: A National Emergency (SANE), a charity aiming to raise awareness and to fund research.

Seven years after *The Times* campaign began, SANE feels it has gone some way to making schizophrenia and other serious mental illnesses more understandable to the public, and that its greatest achievement is the opening of SANELINE, a telephone helpline launched in May last year to offer support and practical advice to sufferers and their families. A research centre for schizophrenia and depression is being planned in Oxford, but £1.75 million is still needed to meet the £6 million target of an appeal launched by the Prince of Wales, SANE's patron, in May 1991. The King of Saudi Arabia has already pledged £1.75 million.

But the disaster predicted in 1985 has not been prevented. More seriously ill and institutionalised patients are being thrust on to community services unable to cope with them. Less care is being provided for the mentally ill being discharged into the "community", which in practice is to families who are often ill-equipped financially and emotionally to cope.

Many former patients still end up on the streets it has been estimated that 40 per cent of Britain's homeless are mentally ill. There are still sufferers who receive no supervision, no medical treatment and who cannot gain admission to hospital.

This week, following the case of Ben Silcock, the 27-year-old schizophrenic who was mauled by a lion at London Zoo, the health secretary, Virginia Bottomley, announced she is to hold talks aimed at reforming the Mental Health Act. In particular, she is concerned with patients who abandon treatment after they leave hospital care.

SANE has welcomed this review but believes that what is needed urgently is a reverse of the trend towards community care without professional back-up, the provision of the support and medical care that families and sufferers need, and the halting of the closure of psychiatric units.

"It was as though, untested, the government decided to put this cure-all, community care, into the water supply in the vague hope that it would be the answer to everything, from mild anxiety to chronic psychotic disorders such as schizophrenia," says Marjorie Wallace, now SANE's chief executive.

"For ten years we have spoken out about the dangers of forcing community care policies on to communities which are ill-equipped to cope or care."

This article was published in The Times on 5 January 1993

A CARING COMMUNITY?

The plight of Britain's mentally ill

It was a startling idea: to release the mentally ill from asylums and put them back into the mainstream of life, into a caring community. It was a plan born out of compassion, optimism and the discovery of new drugs which controlled some of the most crippling mental disorders. It started 30 years ago and it has been pursued, as a policy, by every government since. At first it worked. But now, 25 years later, the optimism has run dry, the compassion looks threadbare and in too many instances the forces of commercialism are all that is being brought to bear upon the problems of progressively sicker people as they are uprooted. So far, 60,000 patients have been returned to the community and more continue to be as the old asylums like Liverpool's Rainhill Hospital (right) are demolished. For many people, as our investigation shows, the concept of a caring community amounts to little more than a sick joke.



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Mohammed sits on his bed in an unheated basement room in the Keswick Hotel South sea, a labyrinth of dark and dank and squalid rooms filled with more than a hundred of society's outcasts. He was discharged over a year ago from St James's mental hospital in nearby Portsmouth, not because he was cured but because it is Department of Health policy to reduce the number of long-stay patients in mental hospitals.

"The nurses told me it would be good for me to live out of the hospital. They drove me to a building. Told me to sign on. But St James's is my home," he says.

His room is about 12ft by 6ft, more depressing than any prison cell I have visited. A bare electric bulb hangs from the ceiling and on the wall is a single-bar heater with a coin-in-the-slot meter.

Mohammed seems confused about the meter and does not appear to use it. There is a table with a mug and an electric kettle, a cupboard and a rotting chest of drawers. He opens them to

reveal no personal possessions, no change of clothing, only an electric light bulb, and two damp army uniforms adorned with "medals" - a few badges and a glass brooch from a cracker.

Mohammed believes the Second World War is still on, but cannot remember on which side he is fighting. "I was chauffeur to the Sultan of Zanzibar," he says, grinning broadly through toothless gums. "I came to this country when I had a breakdown."

"I worry about him," says Vicky, his landlady. She came to the Keswick seven years ago as the cleaner and some time afterwards moved in with the manager. "Mohammed sometimes says he wants to kill himself. He believes if you die by fire, God will forgive. There's always the risk he will try it out - and there are mothers with babies in the hotel. He can't manage his money and he's not eating. No one visits him regularly."

The Keswick is not the most welcoming hotel. Warning signs are fixed to the gates: BEWARE GUARD DOGS. Two Rottweilers are barking savagely in the mud and rubbish of the back garden and gnawing at giant

bones. A marble headstone in the wasteland is a memorial to a deceased Rottweiler. Posies of plastic flowers decorate the mound. "We had a lot of problems with people coming over the wall and that," explains Vicky. "There'd be people sleeping in the lavatories and disappearing without paying. Now they don't." As if to make a point a dog barks loudly. "I'm fond of the dogs, I prefer them to some of the people we get here."

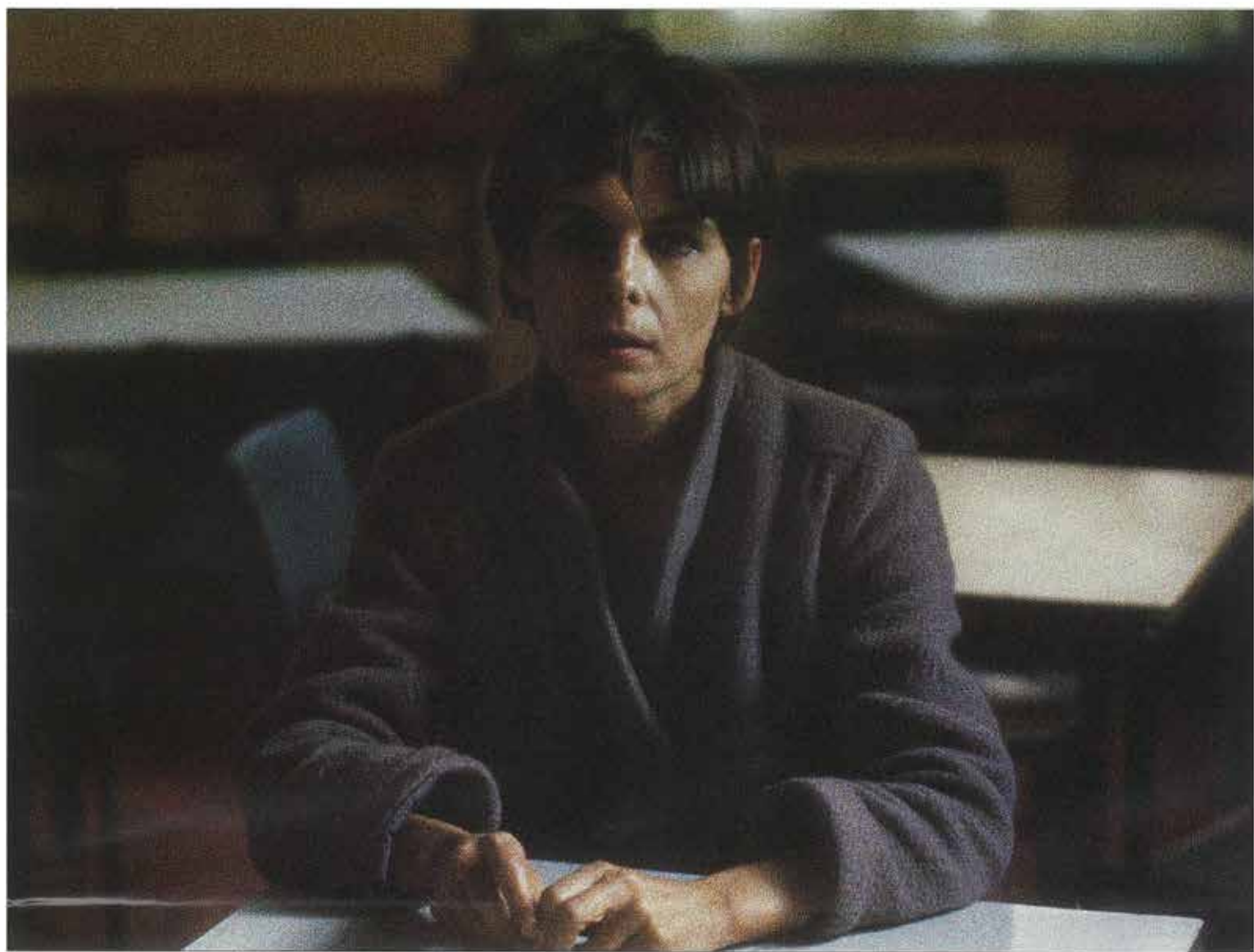
Vicky is conducting the interview in her cluttered room. The centre-piece is a four-poster bed, ornately curtained. Two enormous pink and yellow teddies sit on the lace bedspread. More than 20 brass statuettes of alsatians and many photographs of dogs are grouped on the tables. One wall is strung with the manager's collection of weapons, mainly knives. Around the room in glass cases and wall cabinets are dolls; row upon row of them, china, plastic, cherubic, crinolined, their wide-eyed painted faces staring across the room at the steel blades.

"They're turfing them out of the hospital and it's not right," says Vicky in a depressed monotone. "Sometimes they'd ring and ask us

to take a patient and tell us what was wrong. Sometimes the patient would come straight from the ward and we'd be told nothing. We had about 15 of them two years ago. They'd seem all right when they came. Then they'd go a bit funny." Vicky gives a quick rundown on her clients. There was Ronald, who failed to go for his injections and became violent. Vicky says she rang St James's but nobody came for a week. Another man jumped out of an upstairs window soon after he arrived. And an ex-solicitor spent his days standing like a statue on the street corner.

"When these people leave you've got to gut the rooms - they wee the beds, leave dirty clothes. The smell is awful. To be honest, I'm refusing people from the hospital," Vicky confides. "This isn't the place for them. It doesn't help them. If they don't wander the streets, they sit on their beds and stare at the walls all day. It's not a normal life. I've dealt with dozens from the hospital. Some of them we've had to ask to leave. I don't know where they go."

The Keswick Hotel is only one of 900 houses in Portsmouth registered for mul-



To fill endless days, Peter (right) returns to hospital for gardening therapy, but that, too will soon change

tiple occupation. They once catered for holiday-makers but the number has multiplied almost five times during the last seven years as landlords have discovered the attractions of a new clientele. The most unwanted – the homeless, unemployed, ex-prisoners, drug addicts – have now become favoured currency in bed-and-breakfast land. The DHSS pays their rent regularly by giro-cheque, the business is not seasonal, and the customers have neither the status nor the credibility to complain.

To this assorted flotsam of society have been added, in recent years, mental patients discharged from hospital according to the philosophy that they should be returned to the community. Village communities always tolerated their mentally ill. Surely in our enlightened times we should do the same?

The move back to the community started in the Sixties. At that time, too, there was excitement that the most distressing symptoms of mental illness could be controlled with new drugs, so that sufferers, after a short spell in hospital, would become stabilised and return home. New psychiatric units were planned in district hospitals so that mental illness could be



treated like any other, without stigma.

At first it looked a humane and progressive idea. Those who were least ill succeeded in holding their own in the community. But what started as a welcome release of people, many of whom had been put away solely for the convenience of society and relatives, has taken on disturbing dimensions. This vast social engineering experiment in which an estimated 60,000 or more mental hospital patients have been returned to the community has become a problem of human disposal, involving the uprooting of progressively sicker and more dependent people.

The operation is not yet complete. Only one of the

old asylums, Banstead, has finally shut its doors. Between 30 and 60 more will close in the next 10 years, decanting at least another 10,000 patients. The Department of Health admits that it can only guess at the figure. Nobody can foresee the scale or difficulties of this final chapter in the exodus.

So where have all the patients gone? And where will the thousands still to be discharged find a place in the community? Lord Snowdon and I set out to discover what happens to them. We visited resorts like Southsea, deprived inner cities, a northern seaside suburb, a rich farming area and London itself.

We heard from hospital

Top: in a sunless canteen in a London hostel for homeless women, Lydia, who has suffered mental anguish for as long as she can remember, shifts from table to table, fleeing phantom pursuers

Right: Mohammed stands by the grave of one of the dogs which guarded the Keswick Hotel in Southsea



managers about the problems they face in reducing beds; we talked to social workers and community psychiatric nurses; and we saw ambitious blue-prints for rehabilitation hostels, sheltered flats, day centres, crisis intervention units and a complex range of multi-disciplinary services which, given enough money, could be provided around local hospitals and health centres.

Hopes for community care run high and the drive to demolish the Victorian "cities of madness" suits everyone; the Department of Health will be relieved of the escalating costs of running them and will benefit from the sale of the buildings and parkland, local authorities will have their funds boosted and the libertarians will succeed, they believe, in transforming the quality of life for the mentally ill.

The brochure language of the community care enthusiasts does not, however, reflect much of what we saw. A few (we suspect very few) ex-patients were flourishing in model schemes, such as group homes supported by the health and social services. Others were living in a neglected kind of independence in flats or bed-sitters. Many were at home, destroying not only their own lives but those of their families around them. The rest were in bed-and-breakfasts, dismal lodging houses, night shelters and on the streets. Most had never seen - and were hardly likely to see - the proposed "places of excellence".

"No one should be discharged from hospital before a satisfactory pattern of living is awaiting him," says Norman Fowler, Secretary of State for Health and Social Security. But such thinking does not take account of human nature. A "satisfactory pattern of living" often means bed-and-breakfasts run by "caring landladies". Some indeed may be caring, but the majority do not fit the department's image of motherly figures dedicated to their guests. They do not want their homes to be used as rehabilitation centres for people whom the most skilled nurses may have found difficult to help. They are simply letting rooms to anyone with a DHSS giro. (In some hotels, the proprietor is not even on the premises. They are owned by syndicates of absentee businessmen who find the most convenient person, such as a resident, to act as manager.)

Few landladies have been informed about mental illness or how to handle it. Joan Brown, who owns two Southsea guest houses, makes her own curious assessments. "If they're mentally handicapped in the arms, they're all right on the first floor. But if they're mentally handicapped in the knees we give them a ground floor room."

"We're not nurses, you know," Alan Lloyd, her manager, joins in. "But we take their pills from them and give them out. We don't know what they are. We just read the labels."

Joan, whose features

reflect a harsh and defeated life, is a divorcee in her forties. Recently she has had four serious kidney operations. Alan, about 10 years her junior, was a resident sent to her by the probation office. He has now moved in with her and helps run the two houses. They charge up to £55 a week for full board. They try their best, but the place is sad and inadequate.

"We're not getting many referrals now," says Joan. "But we had St James's on the phone last week wanting us to take someone. I refused straight away. Within half an hour Queen Alexandra's Hospital was asking us to take back a mental guest. He'd been sleeping rough."

Joan and Alan admit they open some of the giro-books sent to their lodgers, taking what is due and returning the rest. "It comes through the post, so indirectly it comes to us," says Alan. "We don't give the awkward ones all the money at once, because they stir up the others." The commandeering of giro-books by landladies seems to have been a common practice until the social security offices clamped down on it last year.

Max Millett, general manager of Portsmouth's mental health services, denies that people are being directly discharged into places like these, but admits the nature of mental illness means that disturbed people leave or are evicted from the better homes. "We have a clear policy of discharging only into places we consider adequate," he says, "but we have no powers to deal with the standards of accommodation, if people exercise their right to leave what we have found and drift to the cheaper end of the market, we cannot stop them."

Portsmouth was one of the first places to move into community care and there are only 360 patients left in St James's. Two hundred of them are elderly and will be rehoused in new buildings on the site. The rundown is almost complete, and Millett is proud of the record. "There are between 750 and 1000 people who need or have needed psychiatric nurses, the highest number per head of population in the country."

Planners like Millett envisaged a range of accommodation, appropriate to the ex-patients' needs. The most dependent should go to small hospitals or to mental nursing homes which can charge high fees for 24-hour care. For the less sick there would be residential care homes, registered with the social services. These homes require, depending on the number of guests, between two and three care staff, one of whom must have a year's experience. They must be open to inspection every six months and can charge up to £150 a week per guest.

Such homes have become popular investments for psychiatric nurses who see little future in the hospitals. "We realised our jobs were on the line," says 26-year-old Sue Goward, who set up in



Rainhill Hospital, serving the Liverpool-Southport area, was closed in 1992. This patient is one of 850 who have been 'relocated'. Once the largest asylum in Europe, in its last days it was described as being 'more like a transit camp.'

business at Whitehaven Court, Southsea, with Ian Firmin. Both were psychiatric nurses at St James's. "We decided to do something on our own. They were having a massive turn-out at the hospital so we said to some of the patients: 'Come and see if you like it.' They did and we've never had a spare bed."

They need a full house to make a profit after paying for food, staff, laundry and maintenance, plus the repayment on a £74,000 mortgage. The 13 ladies, all from the same ward, provide an income of just under £90,000 a year. Sue Goward says she draws only £75 a week and works more than 100 hours. Guests also help out. "We try to make them do things for themselves and help with the cleaning and

manager of a night shelter and former director of Stonham Housing Association. "There is no way of anyone knowing what really goes on."

Neighbours also worry about the private "mini hospitals" being set up in their midst. They complain that the Whitehaven ladies look unkempt and can be seen wandering about the seafront at all hours. "There's one woman comes in with a summer dress and canvas shoes in the freezing weather," says the local landlady at the one pub which does not ask the Whitehaven ladies to leave. "She picks up people's glasses and fag-ends and mutters away to herself."

Sue Goward defends what she believes is an improve-

The majority of landladies do not want their homes to be used as rehabilitation centres for people whom the most skilled nurses may have found difficult to help.

washing up," said Sue. "We have a reward system. If they help they get cigarettes or a pair of tights."

There is considerable rivalry between the ex-nurses to acquire the better-behaved patients. "There's quite a lot of poaching going on," says one of the first nurses to leave St James's. She has run a nursing home for 24 ex-psychiatric patients for the past 11 years. "It's getting difficult to find residents. One man who lived with us for six years went to stay with another nurse who was opening a new home. Not long after," she adds, "he committed suicide."

"The trouble in the private sector is that it is unstructured and unsupervised," says Terry Hammond,

ment in the lifestyle of her residents. "In hospital they'd have to ask to go out. Now they just go," she says. "They become more independent and integrate with the community."

But the community does not always agree. As we talked to the locals in the pub, Vera (not her real name), whom we recognised as one of the Whitehaven residents, walked in. A timid, middle-aged woman, she bought an orange juice and sat down. The others edged away. "You can't really talk to her," they warned. It was indeed difficult to hold a conversation. Vera whispers like a scared child, nodding, smiling, but making no sense. We left her sitting staring at her orange juice, as isolated from the

community around her as if she were in a locked ward.

The trouble is that independence may simply mean loneliness. No matter what facilities there may be, the onus is always on individuals to seek out ways of occupying themselves. Even for healthy people, this requires an effort of will and motivation. For the mentally ill, the black dog on their shoulders and the daily struggle against the voices and hallucinations is often too draining for them to be able to get out of bed, let alone go to a day centre or health clinic. Some make the effort, but most roam the streets aimlessly, or sit lined against the wall in dreary sitting rooms, mindlessly gazing at the television - just what the reformers most condemned in the old institutions. A few, like Mohammed, return to their former hospital homes, now like ghost towns, to wander about the grounds, haunt the corridors or take advantage of some companionship in the cafeteria.

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In the more genteel seaside resort of Southport, on the Lancashire coast north of Liverpool, the National Schizophrenia Fellowship has tried to combat the loneliness of discharged patients by running a drop-in centre, funded by grants from health and social services. Janet Williams, a cheerful woman who is herself handicapped by multiple sclerosis, manages it. "We get about 20 to 30 sufferers every day. But we are only open in the afternoons, Monday to Friday. The rest of the day and at weekends they have nowhere to go."

Southport has 2000 homes registered for the care of the elderly but only 60 residential beds for the mentally ill. The rest live in bed-and-breakfasts. "I get so depressed, I don't get up for days," says Linda, a pretty 25-year-old who has been in and out of hospital after a succession of suicide attempts, including setting fire to herself.

Loneliness, especially of "difficult to place" young people, is not one of the factors taken into account by the new breed of mental health services managers, appointed in the past two years as a result of an inquiry conducted by Sir Roy Griffiths, whose report recommended the introduction of general managers instead of teams at regional and district level.

"We are a sickness business and should be directing resources to the treatable end of the market," says Roy Williams, unit general manager of Rainhill Hospital between Southport and Liverpool. "The National Health Service should not need to make long term provision for young chronically mentally ill. They should be provided for in the community."

Williams has the task of emptying the hospital by 1992. Rainhill was the largest asylum in Europe. In its heyday it contained 3000 patients and its sturdy brick

villas and imposing towers dominate 300 acres of parkland. But as it has emptied, the grandeur has faded.

Already the bulldozers have moved in, demolishing two wards. Patients, now transferred to other wards, wander among the rubble. Staff morale is low. "It's more like a transit camp than a hospital," says Gordon Beirne, the hospital representative of the National Union of Public Employees.

As in Lincoln and other areas where wholesale closure of a hospital is being planned, the nursing staff are running pockets of resistance. "The social workers come and say they are opening a new home and ask us to give three of our best," says Vivien, a staff nurse. "But on our kind of ward we have no 'best'."

"We are talking about the final chapter," says Williams. "Our first step was to find out where patients had originally come from and to return them to their own communities. Already those patients that could be resettled easily have gone."

The remaining 850 are elderly or have severe behaviour problems, and 180 are displaced persons with no traceable roots. For them a series of small hospitals, hostels and sheltered flats are being planned in conjunction with local authorities, housing associations and charities. But so far, scarcely a brick has been laid.

Many of the patients are being transferred with a "dowry" attached to them. As they close the bed, the hospital hands over some of the cost of keeping the patient in hospital (around £400 a week) to the local authority. Each district makes its own deal, offering from £7000 for a limited period to £15,000 a year in perpetuity for each discharged patient. "In order to release the funds, I have to reduce beds. I can only work within cash limits," says Williams.

Whatever his pressures, Williams claims that patients will not suffer. "We will not discharge people into private accommodation or anywhere that is not a demonstrable improvement in the quality of their lives."

Despite William's firm assurance for the future, we found numbers of patients already diffused into the community, in lodging houses, hotels or worse.

Other complaints are that once a patient is discharged it is very difficult to get help, or even return him or her to the hospital. Ron Wareing manages the Turner Memorial Home in Liverpool, a rest home for 52 men and boys including six patients from a long-stay ward in Rainhill. "We have had problems with backup," he says. "Once the social worker has delivered them by car, that's it. The hospital refused to take back a man who was sexually molesting one of my staff because they said we were out of their catchment area."

The home looks and feels wax-worky. The building, approached by a long drive-

way, is patrolled by three security guards. Inside, it is clean and quiet, with numbers of uniformed staff tending the guests. Rows of men, some senile, some prematurely old, some mentally ill, sit fittingly immobile alongside the marble memorial to the home's benefactor. But at least the place seems well-run and the guests tended.

Ron Wareing is worried about those patients who do not fit into a home such as his. "They end up in places for the homeless or unsuitable hotels."

Aber House on the fringes of Toxteth looks run down, even by Liverpool standards. Plastic flowers here and there fail to divert the eye from the layers of dirt covering the dining-room tables and embedded in the chairs. Maureen King, who runs the hotel, has also learned to refuse patients from Rainhill. "The social worker from the hospital rings up and says: 'We have a person here, can you manage him?' I ask the usual questions - Is he very ill? Is he on medication? Is he incontinent? - Then this fellow is dropped off on my doorstep. Half the time when they come out of hospital they are so disorientated they can't cope. If they are on medication I dole it out, but I'm not a nurse. I don't consider it my job. I don't pretend to help them. They should be in proper rehabilitation places. We're just a private hotel."

Even more alone than those in hotels or lodgings are the ex-patients living in council flats, sometimes 12 or more floors up in half-empty blocks. Some of these blocks, like Logan Towers, are due to be demolished and are in the most desolated areas of Liverpool, rising over a wasteland of rubble and barbed wire, rife with muggers, vandals and drug traffickers.

The ex-patients may have been given their freedom; but there are no safe grounds to walk in, nobody (except an occasional visiting community nurse or social worker) who cares whether they ever go out, take their medication or eat properly. In high-rise blocks like Logan Towers or St George's Heights, neighbours have little time for other people's problems - especially if those people are aggressive or withdrawn.

"We know dozens of them," says Lily Brumhill, who works at the Vauxhall Community Centre in one of Liverpool's poorest districts. "There's nothing more depressing than living in those high-rises. People with mental problems are just left to get on with it."

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Tired with seeing the seedier results of the closure programme, I asked the Department of Health to show me places where the transfer from hospital to community care was working best. It gave me a list of eight areas. The top three district health authorities were Aylesbury, Kidderminster and Yeovil. They were followed by North Derbyshire, Brighton, North



Devon, West Dorset and Harrow, Middlesex.

I chose Yeovil, a prosperous market town in Somerset where average incomes are among the highest in the country.

The Department of Health was reluctant to give away clues as to why Yeovil had been selected as a showpiece. "Go along and find out for yourself," was its helpful reply.

As suggested, I rang the local authorities and the manager of Somerset's mental health services. In many ways, Yeovil is well served. The nearest psychiatric hospital is Tone Vale, 25 miles away at Taunton, so Yeovil has been among the first to build up facilities for the mentally ill within the town.

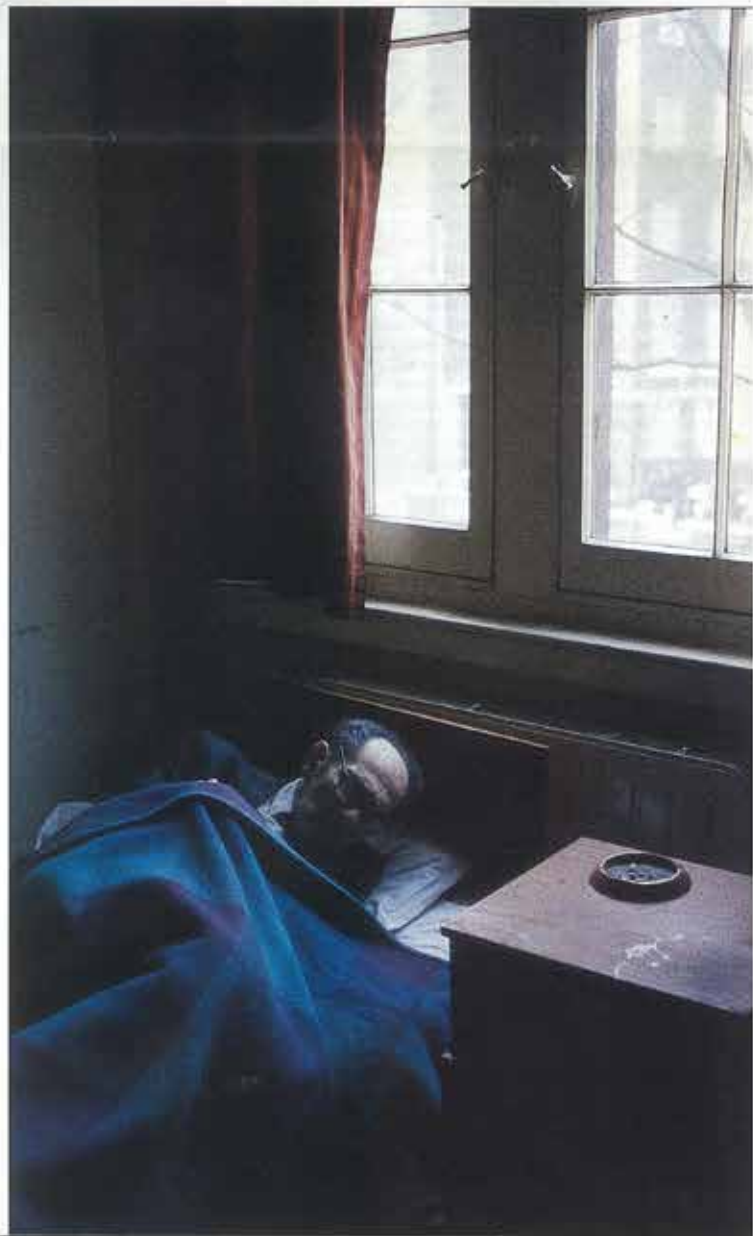
There is a 28-bed acute psychiatric ward on the ninth floor of the district hospital (known, since the adjoining ward is for gynaecology, as the "fruit and nut" floor). There is a luxurious home owned by a housing association and run by MIND, the National Association for Mental Health, prettily designed with duck-egg blue walls and seven bed-sits. Since no one wants to leave, there is always a list.

There are two more group

Bob Halpin (top) was found living in a council flat with no light, no food and a litter of nine puppies on the only mattress. He was too ill to ask for help and in a dangerous state of self-neglect. After a brief stay in a psychiatric unit, Bob was returned to the same flat - still with no electricity - left to roam the streets collecting junk and dosing himself with tranquillisers

Homeless ex-patients provide a steady income for some landlords. But Joan Brown (above) and her manager are refusing them. "We're not nurses," they say. "We can't cope"

For some (right) the struggle against voices, fears and inner torments leaves them too exhausted to get up



homes on pleasant housing estates, and a conversion is planned for a four-bedroom semi-detached house.

There are two day centres: Penn House, which, although it officially caters for 40 people, limits the number to 25 for reasons of space; and MIND's Markwell Centre, which takes a further 20 people and runs a Good Companion Club. There are six community psychiatric nurses, four psychiatric social workers, two psychologists and a crisis intervention team.

Yeovil boasts the fewest admissions to Tone Vale hospital. Council flats are not too difficult to find and even home helps are used as part of the team.

It all looks just what the government ordered. Dr Hugh Koch, the unit general manager at Tone Vale and in charge of Somerset's mental health services - another of the Griffiths men - describes the shift to community care more in terms of the transfer of docile passengers from Concorde to the VIP lounge.

The strategists are confident; their language is full of ellipses and euphemisms: people are not being discharged but "normalised", wards are not closed but "rationalised", facilities are "re-used", even suicides are referred to as "untoward deaths".

"All we are doing is a relocation exercise," says Koch, a self-assured 35-year-old former psychologist. "We would only encourage someone to leave hospital if they were not making proper use of the premises or if there were no real overt problem. They will not be pushed out in an inappropriate way."

"The clinical process would be deciding: 'Is this person ready to go out?..' The standard questions the clinician would ask are: 'Do you get depressed?' 'Do you have thoughts of killing yourself?' We would never let them leave if the risk is too great."

Yet between July and August last year, five Tone Vale patients and ex-patients committed suicide, two on site and three within a short time after being discharged. "They had outpatient follow-ups," explains Koch. "There is no evidence there is any problem of moving into the community." But there have been five further suicides in the last two months; four of them patients who had been discharged into the community.

"Suicide happens as part of everyday living," says Koch. "Two of the discharged patients had appointments for outpatient care. Others were felt not to need such care. Sometimes it's very important to let people have freedom rather than hovering behind their back."

There have been several clusters of suicides around other hospitals which are closing or running down. At St John's Hospital in Lincoln, for example, 15 current or discharged patients have committed suicide in the past 18 months. An inquiry is now being held. Part of the problem is the lowering of number and morale

among the staff as well as the feelings of insecurity such changes create.

Even the most optimistic of mental health planners realise there is a problem with patients who are not deemed dangerous enough to themselves or others to be detained in hospital under the Mental Health Act, who do not think they need treatment and who do not fit into the schemes available in the community. "We would look to hostels or group homes run by social services," says Koch. "If those possibilities are exhausted, we would see if there were relatives prepared to offer accommodation."

It is among groups of these relatives that the bald patches in Yeovil's luxury mental health services show up. Research has shown that returning to the family caused maximum damage to patient and relatives alike. Their testimonies provide the most poignant indictment of community care.

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One after another, I listened to stories of neglect, loneliness, even terror, as parents, many ageing and unwell, described how they were forced to provide the care the health service no longer sees as its responsibility. They are left to live in the same house or isolated farm with a disturbed son or daughter whose illness makes normal relationships impossible and who frequently lays siege to his or her own family.

"We live in fear of our children," says Marina, a lively, compassionate woman whose son came in while we were talking and threatened her with violence if she revealed his name. (We have changed the names of some relatives and sufferers.)

A good-looking man of 27, her son has been in and out of hospital since his first breakdown at the age of 15. When he left hospital five years ago he was given one of the flats run by MIND but within nine months he had become so aggressive he was asked to leave.

"Everyone insists on treating his behaviour as a social problem, not a medical condition," says Marina. "He muzzles and black-mails us, but we can never get help."

"The crisis intervention team can do nothing. Their purpose is to defuse the situation, keep the patient at home and prevent a hospital admission. But it is precisely because we can't keep him at home that we have called them. Community care is as big a disaster in Yeovil as in the rest of the country."

I met a tough and spirited woman of 85 who drove over 20 miles at night to tell me her story. She dared not invite me to the home which she shares with her 80-year-old husband and their 43-year-old schizophrenic son. "I had to slip out of the front door while Michael was coming in the back. If he knew I was meeting you he would be very aggressive," she says. "He likes to grab my glasses and smash them into my face. Last time I left



Linda, 23, spends several afternoons a week at the National Schizophrenia Fellowship's Drop-in Centre at Southport. She lives alone in a bed-sit and has made frequent attempts on her life. "Some days I'm so depressed I don't get up," she says

him for a night, Michael attacked my husband. Our son is 6ft tall and very strong," she says.

"The following day the social worker arrived. Michael fetched the tractor, lifted his car and wrecked it. That was nearly a year ago. He hasn't been back since." She recalls the story with some relish, as do the rest of the self-help group to which she belongs. So angry are these normally restrained middle-class mothers that they, too, would like to lash out against the services they feel have failed them. At the same time they are afraid: "We can't complain because the little help we get would be taken away," says another mother.

★ ★ ★ ★ ★

Tom and Jenny, a charming, hospitable couple, were shocked when their son Robert, a gifted art student, first became ill. "At 23 he came home in a terrible state," says Jenny. "He is not rough by nature, but when he gets ill his behaviour gets unpleasant and frightening. He couldn't bear the light and would remove all the bulbs or hang his underclothes over them."

They have tried and failed to get help for him over the past five years. Inevitably his condition worsened. The trouble is that the social worker and doctor are impotent in the face of someone

Robert has been allowed by the district hospital to live in the community - and to play havoc with his parents' lives.

"He found himself an unregistered lodging house for boys on probation," says his mother. "The hospital knew he was there. Yet he was sufficiently ill to be detained under the Act. There is all this talk about rehabilitation. It doesn't exist. They tried to arrange cookery lessons, but we have seen no other attempts to help him."

"Tom and I found Robert walking down the road. One could see the fear mixed with heartbreak in Tom's face as he watched his once talented son slouching along, his shirt hanging out, a strange, faraway expression on his emaciated face. When we stopped the car and offered him a lift, Robert rejected his father with hostility and walked on from nowhere to his barren flat on a housing estate. 'Thank heavens,' said Tom with obvious relief. 'He's in a good mood.'"

Brian Goodrum, senior psychiatric social worker and the local representative of MIND admits that while there are many who benefit from community care, there are some parents who are left with the burden. "If a person is determined to refuse our help, then I would suggest the family precipitate a crisis," says Goodrum. "In these situations we can-

It is not only the parents who need protection, but the sick people themselves. Their illness makes them vulnerable to exploitation, and they are often forced into companionship with less savoury members of society. Last year George was living in a bed-sit in Taunton and met up with tramps and drug addicts who took advantage of him, broke in and stole his money. "He telephoned the landlord, who found him living in absolute turmoil, among broken glass with blood-stained clothes everywhere. He didn't seem to notice. He had called to say a washer was missing from the tap," says his mother.

"We are realistic about his illness," she wrote to her local MP, "but we do believe his suffering would be greatly lessened if he took the medication under strict supervision. How can we achieve this when he is denied the medical care he so badly needs because of his right to refuse treatment even though he is insane and unable to make any sensible decision for himself?"

★ ★ ★ ★ ★

The relatives' cry is echoed by the charities and voluntary workers all over the country who are picking up the casualties of community care, the new vagrants who are "doing the circuit", roaming from one doss-house or resettlement unit to another, or sleeping in cardboard boxes.

The charity workers complain that not only are they getting direct referrals from the hospitals but that there is poor liaison and scant help when it is needed. "There is no one there in the evenings or at weekends," says John Macauley, a care worker from the St Petroc hostel for homeless men in Portsmouth. "We are getting more and more psychiatric cases. If there is a crisis I drive the man straight to hospital. The moment a doctor comes, I run. That is the only way a sick person will get help."

"The new hospital managers don't know or care about the failures who come to us. They are creating new ghettos for the mentally ill," says Emyln Jones, director of the National Association of Voluntary Hostels. "The community is not ready for them."

The situation is becoming worse as night shelters, unable to cope, are closing their doors to psychiatric cases because they disturb other guests. With nowhere to go many find their way to the big cities.

Ken, a caring man with a gingery beard, manages the Queen Mary Hostel in London for 76 homeless women. "At least 70 per cent suffer from identifiable mental illness," he says. "Hospitals and social workers tend to use us as a way of clearing their books. Their vision of community care is a single women's hostel. It's not ours."

He is aware of the inadequacy of what he can provide. "Patients who have been in hospital are used to a clean, structured place and nurses to come when they call. This place is grotty

and we don't have the staff to care for them."

The hostel was indeed grotty. In the enormous day room, more bleak and institutional than most of the psychiatric wards I visited, women were sitting backed in rows against the wall.

"We can provide little to do in the day," says Ken. "We encourage them to go to day centres, but I can't march them there."

We found Lily lying in bed as she does most days. "She came from a psychiatric hospital two years ago," says Ken. "She is obsessed by the idea that she will never die. There's not much we can do for her."

There is almost no privacy and little comfort in the dormitory. Decaying lockers separate the 16 beds. The linoleum floors are stained and cracked, the net curtains heavy with dirt. A dormitory bed costs £31.85 a week, and there are a few cubicles which cost an additional £2.10 a week, but the hostel has to manage within the limits of what they can charge. An evening meal costs £1.85.

Downstairs in a sunless and greasy basement, Lydia, a well-spoken woman in her early forties, was muttering to herself over a cup of tea. "I've been ill for so long," she confided. "Come over to this table where they won't overhear us." I looked around the deserted canteen. "No, this table is safer." As we shifted around, fleeing her phantom pursuers, she told me strings of sad, incoherent tales of hopes and memories. "Can you help me?" she kept repeating.

Across London, in Endell Street, Covent Garden, the St Mungo housing association runs an equivalent hostel for 110 men. "It was originally a place for men in the catering business," says Mick Carroll, the committed young man who runs the hostel. "Now more than 60 per cent are former patients or currently ill. We have only two staff on duty at night. We can't take them to hospital and we can't keep them. One ex-patient recently set fire to his mattress. But if we turn them out, they will probably end up on the Embankment."

It is easy to lose sick people in this way as they move round the country unable, because they are homeless, even to register with a doctor. The Department of Health keeps no statistics on the numbers of mentally ill who become homeless; nor are records kept on many thousands who have left the asylums. They disappear between the boundaries of health areas and local authorities.

To be fair to the planners, this was not what was intended by community care. They blame the failures on lack of finance and planning and insist it will all improve in time; and there are some places in which it does appear to work. But the basic flaw is that the whole social experiment has been undertaken without any evidence that it provides a better way of treating mental illness, and without any

"Hospitals and social workers tend to use us as a way of clearing their books. Their vision of community care is a single women's hostel."

who puts on a show of rationality when they arrive. Even when sufficiently disturbed to be detained under the Mental Health Act,

not intervene and the quickest possible help is the police. But even then, if no offence has been committed, there's nothing they can do."



estimates of the numbers involved. Since the Department of Health can only guess at how many have been or will be discharged into the community it is impossible to ensure that adequate provision is made. A spokesman for the Department of Health said: "We would not expect evidence that the quality of life would be better outside hospital for all chronically severely ill people... A number of studies into the welfare and happiness of discharged patients tend to confirm that after-care is badly coordinated and that the allocation of resources is often haphazard. But the studies show that even when the standard of community care is well below what we would wish, neither patient nor relative wishes for a return to hospital care."

We have been unable to trace these studies and the department has declined to be more specific. Professor Kathleen Jones, Professor of Social Policy at York University, says: "I know of no major study which has been undertaken which follows up the welfare of patients who have been discharged into the community; nor whether patients or families prefer this to hospital care. There is no evidence from the United States, Scandinavia, Italy or anywhere else that would lead us to believe that the closure of hospitals is the right policy for a country to adopt. It was a mish-mash of unproved theory with romantic ideas that patients would leave the hospitals and be borne aloft on a tide of goodwill."

As one distraught mother wrote to me: "With reference to the government policy of discharging patients into the community. Please, what community? I have a schizophrenic son who lives at home. I know that is the safest place for him. But the despair I feel at being so inadequate is almost unbearable. Am I supposed to be the community? Where do I go from here?"



(Top) Independence often means loneliness. Vera, transferred from a long-stay ward to a guest house, nods and smiles, but customers

at her Southsea local edge away, leaving her as isolated as if she were in a locked ward

Malcolm (above) and his wife suffer from mental illness. Their room overlooks this garden at the Regent Hotel, Southport

HAVE THINGS REALLY CHANGED?

In 1987, when 'The Forgotten Illness' articles appeared, they seemed to touch a nerve, like the beginning of a freak wave of change. The outrage with which that exposé of the failure of 'community care' was greeted led to the foundation of SANE.

ANNA KORVING looks at care in the community today.

SAD to say the hopes that were raised for a changed approach to care in the community when "The Forgotten Illness" was published six years or more ago seem to have been ignored in the rush to save money and to reform the Welfare State.

Mental hospitals are still closing at an accelerated rate, and, despite the best efforts of mental health professionals, people are still falling through the net. The development of the Care Programme Approach was intended to ensure that the most vulnerable people would receive the facilities and support they needed, when they needed it. Each patient discharged from hospital would be given an individual care plan, agreed with him, and specifying the type of care he should have.

All of this calls for money to implement, money which does not seem to be forthcoming. Even the appearance of the Mental Illness Specific Grant (MISG) to help local authorities pay for the cost of care has not helped. The MISG, rather than being new money made available where it is desperately needed, is simply 'old money' ring-fenced for a limited period of time.

There are still homeless mentally ill people sleeping rough on the streets of every big city. They are every bit as institutionalised as they were in the large mental hospitals that might previously have been home, only now they are 'in the community' there is no-one to feed and clothe them, or to supervise the medication which keeps their 'voices' at bay.

But these are the unlucky ones - and it's easy to forget that for every homeless mentally ill person sleeping in a bus shelter, there are many others who have not 'fallen through the net' and are on their own or living with their families. How are they faring in this brave new world of Care in the Community?

Peter and Bobby both suffer from schizophrenia and live with their mother in a large decaying house in the outer suburbs of London. Peter has just been readmitted to hospital for six months on compulsory 'section', after attempting suicide. Peter is a familiar figure to his neighbours, as he wanders up and down the road, clad in numerous layers of thick, dirty clothing, even in the height of summer. His distinctive appearance, and the slow shuffling walk caused by his medication mark him out.

Bobby, Peter's younger brother, also suffers from schizophrenia, but the neighbours rarely meet him. Bobby spends up to 20 hours a day alone in his room, chain-smoking and staring at the walls, interrupted only by his mother's efforts to make him eat.

When Peter needed to be readmitted to hospital, it took three months and a suicide attempt to persuade his psychiatrist he was sufficiently unwell to need hospital treatment. Peter had repeatedly asked to return to hospital, but was told he was not ill enough to warrant admission. Once he had given in to the siren song of his 'voices', and attempted suicide, he was finally judged ill enough to be compulsorily detained.

Peter and Bobby's mother is in her mid-sixties, and copes alone with her sons since her husband died. She worries about what will happen to 'her boys' once she becomes too old or infirm to care for them.

The story of Peter and Bobby is commonplace, a standard history for a 'success' of community care. But had their mother not been able to take them home, they might now be in a bed-and-breakfast place; little has changed since those articles appeared back in 1987.

ABOUT THE AUTHORS

Marjorie Wallace, who wrote many of the articles in this collection, graduated in psychology and philosophy before joining David Frost and starting a career in the media. She was a member of *The Sunday Times* team responsible for the thalidomide campaign, and was involved subsequently in running many successful campaigns from system-built housing to deaf-blind children.

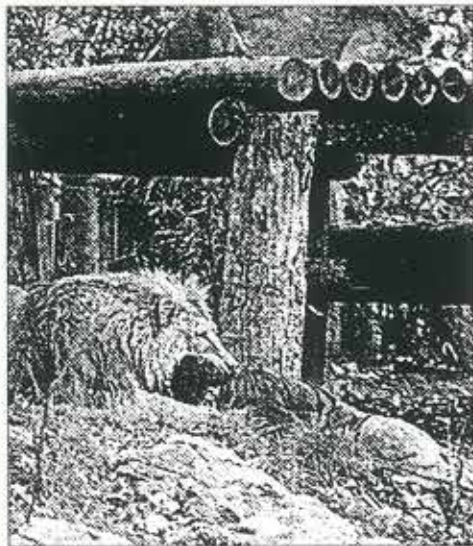
She won eight major awards for her journalism, books and plays ("On Glant's Shoulders" and "The Silent Twins"); appears regularly on radio and television and

lectures internationally.

She held an Oxford Fellowship on campaigning journalism (1989-91), is on the Board of Management of the Institute of Psychiatry and its Ethics Committee, a member of the Mental Health Task Force, and advisor to the Sainsbury Centre.

Dr Timothy Crow is world-renowned for his creative research into schizophrenia and is now Scientific Director Designate of SANE's Research Centre (see page 16).

Caryl Wright is SANELINE operations manager and Hazel Keelan is SANE's information manager.



Can no one help tragic young men like Ben?

by MARJORIE WALLACE

His is just one story of personal torment, but behind it is an illness that brings devastation to a quarter of a million families

HELP FOR DANGER PATIENTS



Reprinted from The Daily Mail, 2 January 1993

THE GRAPHIC pictures of Ben Silcock being savaged by a lion at London Zoo have shocked millions.

What could have possessed this young man to evade staff and climb a 25-foot fence to face certain injury and possible death? The answer, in one shuddering word, is schizophrenia.

Ben Silcock was 17 when he first showed the symptoms of schizophrenia, the mental illness which led ten years later to the near fatal visit to the lion's cage.

The mutilation he endured by the lion, however, is no more savage or shocking than the damage inflicted on him both by the illness itself and by the incompetence, confusion and downright neglect with which he and his family have been treated over the past years.

Schizophrenia is the most common and devastating mental illness, affecting one in 100 people worldwide. It most often occurs in young men, like Ben, between the ages of 16 and 28.

It is not a split personality, a Jekyll and Hyde, but a split from reality which distorts the thoughts, perceptions and feelings of the sufferer.

I know Ben's family well. For several years I have seen at first hand how they coped with the ordeal of his illness.

Ben's symptoms at first

were mainly a change in thinking. He began to drop out and would talk a lot about religion. He had delusions but did not have the acute symptoms which would have attracted more attention.

It was two years before the family had any idea and a diagnosis of what was happening to their son. From then on he went into cycles when he would be disturbed, slipping into months of lucidity followed by more months of disturbance.

Bright

He went into hospital and tried staying in a hostel. It was a long torment for his family who had little support.

They never knew when he would turn up on their doorstep or what state he would be in. When he came home, the stress on both sides made it impossible for them to live together.

He has never held down a job long-term. At one point he even asked me for a job, writing an intelligent and delightful letter. He was very bright and still is, when not overtaken by the illness.

Professionals, authorities and society itself cannot come to terms with the fact that someone suffering from mental illness needs as much or more help than if he had a physical condition. Had Ben suffered from cancer or diabetes he would have been

helped and what happened at London Zoo might have never occurred.

There is no known cause or cure for schizophrenia. In the past, sufferers were likely to spend their lives in mental hospitals.

Chaos

Since the advent of drugs in the Fifties, more have been able to live in the community. However, they still need the care and support which is now often denied.

As in the case of many families, Ben's schizophrenia placed intolerable pressure on the Silcocks, not least for Ben himself.

Indeed the current medical thinking is that adult sufferers are better off trying to lead independent lives.

LET'S SHOW WE REALLY CARE  Daily Mail CAMPAIGN

Some months before Ben's bizarre visit to the zoo he told his father that he had gone to Queen Mary's Hospital, Roehampton, where he attended the day centre, and begged to be admitted as an in-patient.

At this stage in the cycle of his illness he had enough insight to know that he needed to be taken into care and prevented from harming himself or others.

However, he claimed later, because he could speak with insight, he was not considered ill enough to be admitted. As a result, Ben continued to live in his flat on the Roehampton estate, alone, unsupported and vulnerable to the chaos of his mind and external violence.

On two occasions his flat was broken into and he was beaten up. Once he was slashed with a knife and all his valuable possessions were stolen.

He was too frightened to go to the police and when he and his family asked the council for him to be transferred to a less dangerous area, the request was refused.

His father, journalist Bryan Silcock, is angry at the mention of the words 'community

care'. In this he echoes thousands of other parents I have met when he says 'care what care?'

Six weeks ago I was sharing a desk and telephone with Bryan at work. It was a Christmas colder than this year. Ben had been discharged from hospital, although, according to his father, he was quite unable to fend for himself.

Bryan was at the end of

his tether, no one would take responsibility for his son. The hospital said he was well enough to make his own decisions. The police have so many mentally ill people who are homeless that they could not help.

Eventually Ben was found sleeping on Hampstead Heath. Significantly, during this time he had slept in a straw pen at the little children's zoo in Golders Hill Park. On another occasion Ben was found in a pound of guard dogs.

Distraught

During the next years Ben continued to slip between times of lucidity and times of torment when he was quite unable to cope with his flat. He would often rip out all the electric wires, or smash the telephone because he believed it was bugged.

He would nail up chests of drawers because he thought they were contaminated. He would lash out at people if he believed, for example, they were hurting beloved animals.

Occasionally he would turn up on his parents' doorstep, distraught. At no time, according to his father, did he seem to have continuity of care.

Communication between the doctors, social workers and the family, was, as is the case with thousands of people I know, meagre.

One particular incident

upset his father: a drop-in centre run by a mental health association took Ben to court for a minor physical assault and banned him from attending.

Each time he goes for assessment he appears to see a new doctor. His family have been treated on occasions as though they were to blame or have exaggerated his condition. The cruel catch of the illness is that to get treatment someone has to be too ill to know that they need it.

Ben was alone over Christmas. His father took him out to dinner just before the holiday and visited him on Christmas Day at the flat. It seems that there was no one else to see him.

A New Year resolution for those shaping policies might be to stop being hoodwinked by so called enlightened views that claim people like Ben choose to live as he did. After all, this unhappy man believed he could only find warmth and care in the company of animals.

Would any healthy individual really choose to sleep rough on a frozen bench? Hospitals should at last learn the lesson that the next person they turn away could be another tormented man like Ben.

Marjorie Wallace is chief executive of the mental health charity SANE

Readers say: IT'S THE SYSTEM THAT'S INSANE

Reprinted from The Daily Mail, 7 January 1993

At last a national newspaper is taking up the plight of the mentally ill in the community. The tragic case of Ben Silcock climbing into the lion's enclosure has brought the suffering of schizophrenics and their families to the forefront.

My brother Brian died in 1987, aged 34. He had suffered from schizophrenia since he was 19. Brian spent years causing damage to things, not people, to ensure he would be sent to psychiatric hospital under a Mental Health Section Order.

Unfortunately, these orders could be obtained for only limited periods and once Brian was released, he would refuse to take his medication and doctors

could not force him, or they risked being charged with assault.

Finally, on an icy winter morning, the body of my brother was found in the River Cam.

MARY HODGE
St Ives, Cambs

...Community Care, as practised today, is a cruel hoax and a despicable cost-cutting exercise in which the weakest, as usual, go to the wall.

The old hospitals, condemned as 'bleak Victorian institutions', offered warmth, comfort, security, regular meals, medication and pocket money, plus occupational and recreational facilities.

The word 'bleak' is more

appropriate for the future of these helpless, vulnerable patients, now being forcibly re-located.

(Dr) MARGARET MAISON
Swanage, Dorset

TOO LITTLE HELP THAT COMES TOO LATE
How good that Virginia Bottomley has read an article in the paper and plans to improve the situation for the mentally ill.

But why did she not realise the situation before, when it has been common knowledge for years? And why does she think the solution is compulsory treatment? Ben Silcock had asked for treatment but was not considered ill enough. What he and many others

needed was support and caring which was supposed to be provided 'in the community', but in practice meant abandonment.

HELEN JARVIS
Ilkeston, Derbyshire

WHO WILL CARE FOR HER WHEN WE CANNOT?

...I have been a carer of my loved daughter for 11 years. She is beautiful, intelligent, gentle and loving. In her first year at university she developed symptoms later diagnosed as schizophrenia. She suffered much anguish and torment while studying, but managed to get her degree.

Sadly, she has never been able to use her education in

a productive way. Her illness worsened and she has spent 11 years in and out of hospital, after several suicide attempts.

My husband and I cannot leave her unattended for too long, for fear that she will make another attempt. Much of her life is spent in her room, where she feels a little safer.

My husband is nearly 68 and I am in my 50's but with a heart condition; we live in fear of the day when we are no longer around to give our daughter the love and support she so desperately needs. Who will care for her? Nobody, under the present system.

Name supplied
Leamington Spa

THE STRAIN

I am a manic depressive and this illness is dealt with by the same people as the schizophrenics... If you suffer from a problem of the mind, you are looked upon as odd or eccentric. I have long periods of sheer bliss, then I get the depressive side and am laid low for weeks.

It's a terrible strain just living, for me and other manic depressives, so those with schizophrenia must have a wicked time living with the problem, knowing what they might do and that there is not much help at hand.

I hope and pray Ben Silcock will survive and have a much more peaceful life.

(Mrs) NOLA STURGES
Nottingham

LET'S SHOW WE
REALLY CARE



Daily Mail
CAMPAIGN

ANATOMY OF A CAMPAIGN

On New Year's Eve 1992, Ben Silcock, a 22 year-old schizophrenia sufferer who alone "in the community", picked up a brace of frozen turkeys, went to the Zoo, and climbed into the lions' den.

Ben's drama led to the biggest ever schizophrenia awareness campaign. Marjorie Wallace, on holiday in a remote corner of Norfolk wrote the article opposite for the Daily Mail. When it was

published on 2 January, the health secretary, Virginia Bottomley telephoned her promising to review mental health law.

Support flooded in from *Daily Mail* readers. The paper published 12 major articles in a month, including two powerful leaders (see below). Television and radio and other newspapers took up the cry, and millions were made aware of schizophrenia and the work of SANELINE.

A shaming indictment of civilised society

Reprinted from The Daily Mail, 7 January 1993

BOSNIAN refugees make news. AIDS victims, if they are stars of screen or stage, make news. Famous hospitals battling against closure make news. But, until last week, seldom has the scourge of schizophrenia hit the headlines.

When a young man was savaged in the lion's den people wanted to know who he was and why he had climbed in. The *Daily Mail* discovered Ben Silcock's story and told it. Schizophrenia became news.

We told of the anguish of his parents; of the bright and musically talented boy plagued by sick fancies, who became ever more frequently divorced from reality and all too often distanced from those in society who could and should help him.

The response of the Secretary of State for Health, Virginia Bottomley, was commendably swift.

She announced a review of the working of the Mental Health Act of 1983. She admitted how concerned she was that young people like Ben could fall through the safety net. She suggested it might be justifiable to introduce compulsory treatment orders for a minority of mentally ill people who may be a danger to themselves as they wander helpless, confused and not without menace in the community which is supposed to care for them.

An urgent and sensible reaction.

Astoundingly, the Health Secretary was attacked in some quarters of the Press for making so well publicised a fuss about an 'isolated' case.

Where do such pundits live? To whom do they talk? Have they no eyes to see? There are hundreds of thousands yes,

hundreds of thousands of Ben Silcocks in our land.

Schizophrenia is a common place affliction. Gathered together, its victims would populate a medium-sized town.

But they are not gathered together. They can be found down every road in the land. Virtually every family knows one.

They drift in and out of care.

They become an almost unbearable burden on their loved ones. When they are at the end of their tether they sleep rough in their thousands in the shop doorways of our inner cities an indictment of civilised society. And the medical help which they so desperately need is fragmented and all too often inadequate.

Schizophrenia may remove its victims to another mental world. But they remain with us and among us. When they



cannot properly look after themselves, they are our responsibility.

That is why the *Daily Mail* is campaigning. That is why Virginia Bottomley responded.

We have roused concern to promote practical action and this is what needs to be done:

1. There are too few hospital beds for the mentally ill. More must be provided. Mrs Bottomley must review the need and calculate the cost.

2. No further psychiatric wards and hospitals must be closed until there is comprehensive care available within the community.

3. Schizophrenics should not be discharged from hospital unless they have a place to live. Their families should be kept informed.

4. There must be more sheltered and professionally staffed accommodation for those who can leave hospital but cannot cope on their own.

5. Health authorities should keep a register of all known to be at risk from severe mental illness.

6. Those on that list should be able to ring helplines when they need treatment, rather than having to brave surgeries and waiting rooms where they may never have been before.

7. Doctors should have authority to treat, if need be compulsorily, those in the community who are registered as at risk. Of course, there is a civil rights issue here, but surely when sufferers are so in thrall to demonic voices that they are beyond asking for the help they want, they should be given it.

Perish the thought that we should return to the unenlightened old days when the mentally ill were shut away for years in grim institutions. Care in the community, whenever practicable, is much to be preferred. But it cannot be had on the cheap and if the price has to be paid for by closure of redundant London teaching hospitals, so be it.

The treatment and support of the mentally ill must be given a higher priority within the budget for the Health Service. We can and must do more for the quarter of a million Ben Silcocks of Britain and for their families.

For pity's sake, let us not replay the cruelty of confinement with the torments of neglect. ●

Yes, we must do more for people like Ben



by VIRGINIA
BOTTOMLEY
HEALTH SECRETARY

Reprinted from The Daily Mail, 8 January 1993

ALTOO often we allow our view of the Health Service to be influenced by television. A fictional series like 'Casualty' or a fly-on-the-wall documentary like 'Jimmy's' may make for strong images and high drama. But their subject matter represents only a fraction of the work of the health service.

Over the past few days, the *Daily Mail* has been examining one of the neglected problems of health in Britain and has courageously identified mental illness, and schizophrenia in particular, as one of the dusty corners where light needs to shine.

By telling the full tragic story of Ben Silcock and his family, it has propelled the issue onto the front pages. Now, however, the full implications of his case - and many others like him - must bring about rapid change.

Long before I entered politics, I spent ten years as a child psychiatric worker in Brixton and Peckham, one of the toughest environments in the country. I encountered a stream of horrific and tragic cases; individuals and their families whose lives had been blighted by mental illness.

I shall never be able to forget this experience at the sharp end. It has made me believe strongly that we should give this illness much greater priority. After all, it claims three times as many victims as cancer.

At Brighton last year, I included a passage on suicide in my party conference speech. A day or so before the Silcock episode, I set out the case for a fresh look at aspects of the law covering mental illness. The initiatives were little noticed at the time.

Despite its inherent tragedies, the Silcock case at least means that people recognise at last that we can no longer ignore schizophrenia and mental illness.

Yesterday, the *Daily Mail* set out a seven-point plan of what it believes should be done to improve the plight of the mentally ill.

There were a host of challenging and important ideas in that list. We are already making progress in many. I have also asked my officials urgently to advise me further on the pros and cons of the *Mail's* ideas.

We have, to be sure, come a million miles in the treatment of mental illness

from the days of our forefathers. Locking the insane out of sight in huge institutions could be both brutal and inhumane.

EVEN 40 years ago, nearly 150,000 patients were locked up in long-stay psychiatric institutions. Today fewer than one in ten of those admitted to hospital as mentally ill are compulsorily detained.

With the shift away from institutionalised care have come dramatic improvements in services based in the community. There are, for example, three times as many community psychiatric nurses as there were a decade ago.

We must, however, complete the process of modernising our mental health services. They need to be local, comprehensive and sensitive.

Services and resources are not, however, enough in themselves. We must help people make effective use of the services which are provided for them. Allowing people wherever possible to be treated in the community, rather than being needlessly detained in an institution, has been an important strike for individual liberty.

But the sad fact - as anyone witnessing the pathetic derelict figures that haunt many of our streets will know - is that there are still too many mentally ill patients slipping through the community care net.

The main issue is not more money or more beds. We already spend £1.7 billion on services for the mentally ill.

But are we doing enough to ensure that these most vulnerable people in the community are protected from harming themselves and others?

That is why I am particularly interested in some of the ideas that are coming forward for the treatment of the mentally ill in the community. I am sure that more can be done to secure better implementation of the existing law in this field - primarily the Mental Health Act 1983.

We need to explore whether the existing powers in this Act are being used as effectively as possible, especially when an illness is considered serious enough for the patient to be readmitted to hospital. It is not always

appreciated that the Act allows patients to be detained solely in the interests of their own health. It is not necessary to show that they present a danger to themselves or others.

In addition, the time has now come to re-examine the case for community treatment or supervision orders whereby patients in the community can be made to take the medicine they need for their treatment. Such schemes have been introduced in New Zealand and in certain states in America.

THERE ARE, I believe, overwhelming civil liberties objections to a power under which people could forcibly be given injections in their own homes. However, there is scope for considering a form of order under which patients would be subject to professional supervision in the community, and could be recalled to hospital if they failed to continue with the necessary treatment.

Such measures would, I envisage, be used only sparingly. This approach would, however, send a clear signal to professionals in this field that they have a continuing responsibility for their mentally ill patients discharged into the community. We must emphasise that treating patients as they are in some hospitals - 'out of sight, out of mind' - must not be reproduced in the community.

Psychiatrists, doctors, nurses, local authorities, patients and relative groups will all need to give their views. We cannot, however, turn a deaf ear to those relatives and friends who too often claim that a patient's condition has substantially - and perhaps dangerously - deteriorated before help has become available.

This will be a good year for shining more light into the dusty corners of health policy. How often do we see the debate dominated by hospitals, surgeons in their masks, operations and the number of beds? It is typical that some have chosen to concentrate in London on the future of one particular hospital.

The real issue is how we build up good local health care - 'parish pump medicine', as someone recently described it for a population that badly needs it. ●



April 20: Four days since he halved his medication, Bryan writes in his diary, 'Very paranoid. The person upstairs is reading my mind and speaking back in a sort of ego crucifixion. The large rabbit ear is because I am extremely sensitive to human voices, like a wild animal'



April 23: A week after halving his Depixol, Bryan is feeling its withdrawal. He has been inspired by Louis Wain's cats. 'They seemed to show a disintegrating ego,' he writes. 'I expected something similar but I am unable to concentrate, so the painting takes on the crudeness of graffiti.'



April 24: 'Why miss a golden opportunity to describe, through paint, total mental disintegration?' Bryan asks in his diary. 'The spots on the brain of the head are real blood to get over the pain. No eyes to see what is going on and a stitched up mouth. I cannot go on much longer.'



April 29: After the last painting Bryan became scared and took 15 tablets of Depixol, but it has not yet suppressed the turmoil in his mind. He feels lonely, fragmented and exposed as on a stage. His twin brother telephoned. 'He renders the spiritual forces thankfully impotent.'



May 2: The massive dose of Depixol has at last taken effect. 'I am almost completely without energy,' he writes. 'This is expressed by the pupa, the torpid state in insects. The bird represents my spirit crushed by the maggot. My conflict is shown by the man with two heads; one is a nose...'



May 6: For the past four days Bryan has kept to the prescribed level of drugs. He has regained an integrated view of his face, but has become a dartboard. 'I feel like a target for people's cruel remarks. I have sweet-talked a girl to suicide because I had no tongue and could only flatter.'



May 14: Bryan has cut back his anti-depressants to one tablet and is tormented by feelings of guilt, especially for the girl he thinks he encouraged to commit suicide. The image shows 'the ego spitting like a cancer cell.' The Roman soldier's leg is a reminder of punishment her family might ask.



May 18: Eight days after reducing the anti-depressant, Bryan's self-image is very disturbed. 'My mind seems to be thought broadcasting very severely,' he writes. 'I have summed this up by painting my brain as an enormous mouth, acting independently of me.'



May 23: 'The blue is because I feel depressed through cutting back on anti-depressants. I am so pleased I have been able to express such a purely mental concept as thought-broadcasting by the simple device of turning the brain into a mouth that I have painted it again.'



May 29: The blue-green outlines of the previous portrait emerge through the shrapnel-blown face. 'The spiders' legs on the right are to express my inhibitions. I feel all the time that I am getting nearer to a more acute expression of my schizophrenia. Perhaps a broken heart is the cause?'



8 June: This portrait shows a featureless rectangular head, abstract and lonely, filled with white blocks and triangles of thought. Bryan still feels under attack, hence the flaming arrows. His spider-leg inhibitions 'radiate out and become less potent as they depart from my brain' which is 'comforting.'



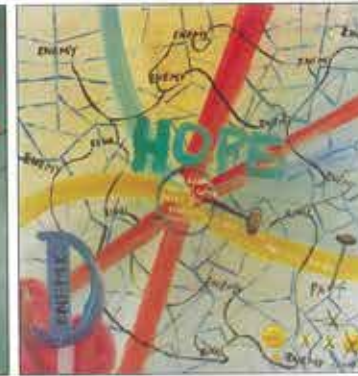
June 13: Bryan cut all anti-depressants from 24 May and his portrait expresses his depression. 'The eggs have been emptied like a head stripped of its contents. They went to satisfy somebody's appetite, somebody that has power over me.' He writes openly of suicide and paints van Gogh's crows.



June 19: 'Do they just want to party...? Everybody has a foot in the door. Nailed mouth and tongue-tied, I have no effective reply to them.' Bryan is slipping deeper into depression. His self-image has been reduced to what appears to be a tiny door.



June 27: 'I make crazy attempts at some sort of control over what has become an impossible situation (the man with the control stick). My brain, my ego is transfixed by nails as the Christ who could not move on the cross without severe pain. So I find I cannot think without feelings of pain.'



July 12: There is no diary entry for this day. Bryan's face has become a battlefield map, his central core of personality like an isolated battalion on a hill holding fort while all the enemies and rivals assemble on the plains beneath. Reason and hope are under siege.



July 19: Bryan Charnley has reached the point of no return. According to Edward Adamson, psychiatric art expert, 'purplish red colours touching on the black come from the unconscious and usually mean suicide.' Red and black meet in a cry of self-destruction. Ten days later Bryan killed himself.

This man, Bryan Charnley, an artist who suffered from schizophrenia for more than 20 years took his own life in 1991 soon after completing a remarkable project: a series of self-portraits depicting his journey through madness, which he hoped would help others to understand his illness.

PORTRAITS FROM THE EDGE

Report by Marjorie Wallace

This article first appeared in The Telegraph Magazine 7 December 1991

At eleven o'clock on a sunny morning in August this year, Father Patrick Bailey was conducting a requiem mass at St Joseph and the Holy Child, a large Victorian church near the centre of Bedford. The doors were open, and from time to time the sound of traffic drowned the priest's voice. A dark-haired woman came forward from her pew and placed a single flower on the coffin.

As Father Bailey blessed the coffin with incense, there was no hint of the measure of the tragedy which shrouded the occasion, no suggestion that a 41-year-old artist had committed suicide in a sad and shocking way. Then, in his short panegyric, the priest described how Bryan Charnley had suffered from schizophrenia since the age of 18 and how, for the next 23 years, he had fought a daily battle against the illness with a 'ferocity and stubborn courage which everyone who knew him respected'.

Yet despite his loneliness and ultimate defeat, Bryan had made one last triumphant effort before he took his life. In a remarkable three-month experiment, the results of which are published here for the first time, he decided to use his skills as an artist to convey to outsiders the experiences he and his fellow sufferers endure.

In a series of paintings he called *Self Portrait*, he set out to show what it is like to live at the edge of human experience, wrestling day and night with spiritual forces of good and evil, darkness and light, reason and chaos. Bryan himself summed up his aim most poignantly: '*Self Portrait*', he wrote in his diary, 'will state in depth what it is to be human and schizophrenic'.

In order to record this journey through madness, he decided to alter the mixture and dosage of the drugs on which he depended

for his relative stability. These were Depixol - one of the neuroleptic drugs which control the more acute and distressing symptoms - and Tryptisol, an anti-depressant.

If he steadily reduced the dose, he could draw back the chemical curtain to expose the features of his schizophrenia and reveal their effect on his self-image. It was to prove a heroic but fatal gamble. On July 29, ten days after completing his final portrait, he was found dead in his flat in Bedford. He had cut his throat.

Of all mental illnesses, schizophrenia is the most common and devastating. It afflicts one person in a hundred, regardless of culture, creed, or socio-economic background. Recent figures from the World Health Organisation estimate that there are at least 55 million sufferers.

All the evidence suggests that the illness is caused by a biochemical imbalance in the brain, which can be triggered and exacerbated by social or emotional pressures. In some cases, drugs can control the symptoms. Bryan himself believed this to be the case, though like most sufferers, he resented the medication which he referred to as his 'lead shoes'. Recent research suggests that there may be a genetic link but as yet there is no known cause or cure.

A myth has grown that schizophrenia is a split personality disorder - the Jekyll and Hyde syndrome. This is not the case. Instead, it is more like a separation from the real world, a fragmentation of thoughts and perceptions, which can radically change, or even destroy, the whole personality. It strikes mainly at people in their late teens and early twenties. About 25 per cent recover completely after their first breakdown, but most remain vulnerable to breakdowns and periods of mental anguish for the rest of their lives.



As *Self Portrait* clearly illustrates, Bryan was a classic sufferer, prey to the most common symptoms. He heard disembodied voices and found special meaning in innocent objects. He would become convinced that people were reading his thoughts or that alien forces had taken control of his mind. He could not, for instance, find solace in television and radio because he believed they relayed threatening messages to him.

The tragedy of schizophrenia is that it affects people who, when they are not in the grip of the illness, are normal and intelligent. And the stigma and blame still associated with mental illness only reinforces their sense of rejection and isolation. As Father Bailey said at the requiem mass for Bryan, 'His illness excluded him from those everyday reassurances and contacts which make life bearable.'

In many ways, Bryan was everybody's idea of the struggling artist. He lived alone, feeling neglected, although he spent most Sundays with his parents. Sadly, as it transpired, his one real tour de force as an artist would be appreciated only after his death. Edward Adamson, an artist who pioneered the healing powers of art in Britain, was greatly impressed when I showed him the *Self Portrait* series. 'I'm sure he would have been very successful,' he said. 'They are all completely honest statements about what it is like to have a schizophrenic illness.'

Bryan recognised the

similarities between his position and that of Vincent Van Gogh, who expressed his mental turmoil through rich textures and bold colours, and Louis Wain, who portrayed his schizophrenia in paintings of cats. For a while one of Bryan's early works hung on the walls of the Bethlem Royal Hospital alongside paintings by Wain. Bryan searched for simple and powerful symbolism so that others could explore each phase of his journey with him. What is exceptional is that however overwhelmed he became by his inner torment, he still was able to retain his insight, to search for rational symbols to express his irrational thoughts.

Several of the recurring themes in *Self Portrait* - the all-seeing evil eye, the pins and nails, the religious imagery - are well known to experts in psychotic art. 'There are single paintings by people with schizophrenic illnesses which convey the same disturbing images,' said Professor Michael Gelder, head of psychiatry at Oxford University, when I showed him *Self Portrait*. 'What makes Bryan's work unique is the intention with which he set out to inform the world of his experiences, and that he completed the series. He does not appear to have done so as a therapy for himself but as a mission to help others at the expense of considerable personal suffering.'

It was this need of Bryan's to persuade the outside world that schizo-

Bryan Charnley (above) depicts himself as an ordinary man, perhaps apprehensive about the experiment he is about to undertake. He suffers from schizophrenia and plans to cut back on his drugs and to paint self-portraits as delusions take hold. (Left) Happier days, Bryan (right) in 1955 with his twin Terry and sister, Celia

Michael Sharp, our volunteer information officer, and I agreed to visit Bryan and Terence in Bedford.

According to Terence, Bryan was excited by the impending visit and hoped that his work might be published. Unfortunately, summer was a busy time and our appointment was delayed until the end of August. It proved too long a wait for someone so sensitive. Terence telephoned to say that Bryan had killed himself. He had left no suicide note, but could it be coincidence that July 29 was the date on which his hero, Van Gogh, died 101 years earlier after shooting himself?

At the funeral, we joined the Charnley family, stunned and bewildered by their loss. Every one of us was feeling the bite of guilt and regret. What struck me was just how neglected the family had felt. From my discussions with his doctor and psychiatrist, it appears that Bryan himself was well aware of his condition. However, his family, like so many, felt they had been left in the dark. They told me that after the first diagnosis more than 20 years ago, they were given no further advice or information. They could think of nowhere to turn, no expert or social worker to contact who could explain what to expect and how to help.

This meant that they were not fully aware of the dangers of his condition and regarded Bryan's behaviour more as studied bohemianism than a symptom of illness. 'My greatest regret is that I did not take more time to look after him,' says Terence. 'But somehow we always thought he would cope.'

Bryan was born half an hour before Terence at a private nursing home in Stockton-on-Tees, near Billingham in Cleveland. Their mother, Mary, was thrilled with her first-born twin sons. 'We got two for



PORTRAITS FROM THE EDGE

the price of one,' she recalls with pleasure. As they grew up, like most twins (they were not identical) Bryan and Terence became emotionally enmeshed and dependent. As three-year-olds, they communicated with each other in a private language. 'It was the two of us against the world. I knew what he was thinking and he knew what I was thinking,' said Terence.

John, their father, was a draftsman for ICI who won a scholarship to study for an engineering degree. With his increasing success, the Chamleys moved to Peckham, then to a large detached house in Chislehurst, Kent.

While they were at secondary school, Terence began to feel the need to break away from his brother. 'I hated being part of a double act and being called "The Chamley Twins"'. We were like an old married couple. I wanted a divorce.' Their mother traces many of Bryan's subsequent social inadequacies back to Terence's attempt to sever the bonds of being a twin. 'Bryan seemed much less able to make new friends. He was always the one who seemed to be left in the shadows,' she recalls. Both boys had prominent teeth, but Bryan felt the embarrassment more keenly. He also found it hard to communicate, his shyness exaggerated by a mild speech impediment.

It was at the age of 18, by which time the Chamleys had moved to Bedford and both boys were attending separate art colleges, that Bryan had his first breakdown. 'He dressed himself in all-white and would talk to us about being crucified,' says his mother. 'He said people were reading his thoughts and became quite aggressive which was not at all like him.' He recovered from this breakdown and completed a prediploma course in Fine Art at Leicester, where he was regarded as a gifted student.

From there he won a coveted place at the Central School of Art and Design in Holborn. Both he and Terence dabbled in the sixties drug culture, taking cannabis and LSD. 'I was all right,' Terence recalls, 'but Bryan was vulnerable. He couldn't cope.'

Bryan became completely withdrawn, almost ceased to talk and would adopt a rigid position for hours at a time. His parents took him home to Bedford where he spent most days in bed, seeing no one, painting only rarely and slowly. After two wasted years at home, at the age of 22 he became so critically disturbed that he was admitted to Fairfield mental hospital. He was given heavy medication and courses of electroconvulsive therapy (ECT) and was diagnosed as suffering from a schizophrenic illness.

He returned home and it was at this stage that some discussion and regular counselling for both Bryan and his family might have alleviated their mutual despair. None was forthcoming. Feeling uncertain and unable to help at a deeper level, Mary and John

urged Bryan to go on training courses and find a job. They even set him up with a window cleaning round.

Unable to sustain any job, at the age of 28 Bryan determined to take charge of his own life and illness and to start painting in earnest. He found himself a flat in the centre of Bedford where he lived alone, like many other artists in a room strewn with unwashed mugs and crowded with canvases. He was proud and refused the help his parents proffered. His daily life was bleak, his horizons cramped by his failure to achieve recognition as an artist. It was a drab contrast to the successful life he had dreamed of before his illness and far from the comfortable family surroundings of Terence who by now was bringing up two children at home in Preston.

Bryan found it difficult to make or sustain friendships, though it appears he had one serious relationship with a woman which ended unhappily, leaving him obsessed by feelings of remorse. He was convinced, probably wrongly, that he had been responsible for her suicide attempt in which she broke her back. She was the woman who placed the flower on his coffin during the requiem mass.

When Bryan was not painting, he spent much of his day sleeping or walking by the banks of the Ouse. In a word he was a textbook example of caring in the community. He had achieved his independence, but could, if he chose, attend sessions at the local day centre. He visited a consultant psychiatrist. He regularly picked up prescriptions from his GP. Social workers were available to help him. Yet they all obeyed the now fashionable rules to encourage independent living, being careful not to intervene, leaving full responsibility with the sufferer.

This policy assumes that the individual is willing and able to seek help. Unfortunately, the very symptoms of mental illness - the delusions, the paranoia, the pride - often prevent that person asking for the help he may need.

'He was a likeable sort of chap, but bitter about the lack of recognition. Had he got it, it would not have cured his illness but would have made his life more endurable,' Dr Martin Simmonds, his GP, told me. However, unknown, it seems, to his doctors, Bryan had decided to confront his illness in hand-to-hand combat. *Self-Portrait* was a lonely decision, with an even lonelier outcome. Surely someone could have intervened to give him respite from the burden of containing his tormented thoughts?

The sadness of Bryan's life and death became even more poignant as I showed his paintings to other artists, including Edward Adamson. 'They are cries, screams for help,' he said. 'It is a pity that you could not bring him to us when he was alive. We could have helped him, accompanied him on his journey and pulled him through.'



So many cries

Since we revealed the true plight of Ben Silcock, the man who climbed into the lions' den, thousands of other families have done just what Ben's mother did that terrible day rang SANELINE for advice, support and practical help in dealing with schizophrenia and mental illness. Here MARJORIE WALLACE selects some of the 893 calls made on the day we started our campaign to help schizophrenics and their families.

From The Daily Mail 12 January 1993

As soon as the lines are switched on they ring constantly - this is one of the first calls.

10.15am James's story could form the script of a horror movie. Last July, his wife, who suffered from schizophrenia and manic depression, was discharged from hospital in Jersey with four weeks medication and little other support. In August, she killed their two children, aged nine and five years, and is now back in hospital.

He is calling to tell us he would like to help our campaign. 'My two children who died, my family and myself are just as much victims of schizophrenia as my wife,' he says. James is very controlled. 'Things were difficult over the holiday period,' he admits. 'I want to make sure this tragedy doesn't happen to another family.'

11.25am Mary, of Belfast, phones in about her 29-year-old son, Tom, currently in hospital. 'I can't find out anything from the doctors,' she says, 'but Tom says that they say he may have schizophrenia.' Mary is not sure what the illness is and is worried about his treatment. 'This drug they are giving him is turning him into a zombie.'

SANELINE gives information about schizophrenia, and the drug he is taking. The volunteer tells Mary about her and her son's legal rights and gives her the number for SANELINE's legal information officer.

12.19pm A desperate, angry call from 76-year-old Brian, of Bexhill, who needs help and support for his 47-year-old daughter Amanda, who has been mentally ill for 36 years. She has thrown all the furniture out of her squalid bedsit. 'She is,' Brian says,

workers seem able to help her.' Brian is angry and frustrated at the years of anguish and waste.

The volunteer puts him in touch with SANELINE's legal information officer, sends information on what carers can do to help and gives local emergency numbers and names of local support groups.

1.11pm Camilla stutters as she tells her story. She was a senior nursing sister but was attacked five years ago and then three years later suf-

which cater for the disabled.

1.30pm Jane phones, a woman in her 30's from North London, who spent three years suffering from a paranoid psychosis - too ill to know that she needed help.

She spent years wandering like a gypsy while no one in the medical profession took any action even though it must have been obvious how ill she was. 'I was in hell,' Jane says, 'but I was too ill to know there was anything wrong.'

Eventually, because a social worker became afraid for the safety of Jane's young son, she was detained in hospital and given medication. She gradually recovered and now wants to pick up the pieces of her life.

She has been reunited with her son, and has married, but still takes her medication. She fears there are many people suffering as she did and wants to help.

2.18pm Joe, a 34-year-old man at his wit's end, rings about his neighbour Alan, who is schizophrenic. Because he cannot look after himself, Joe gives Alan regular meals. But Joe has to go away on business and there is no one to look after Alan, who lives in appalling conditions.

LET'S SHOW WE REALLY CARE  Daily Mail CAMPAIGN

'dirty, and eats very little. Her condition has so deteriorated that if she were an animal you would shoot her. The psychiatrist says she is not a danger to anyone or to herself, so he will not take her into hospital.'

Amanda has tried to commit suicide four times and was hospitalised. 'She came out a new woman,' says Brian, 'but she has deteriorated again. Now she refuses to open her door to anyone and the professionals are unwilling to force it. Neither do her social

ferred a stroke. It left her housebound, with difficulty in speaking. Last year her mother fell ill; Camilla couldn't cope and had a breakdown. She became a patient in a Scottish mental hospital.

Now she suffers panic attacks in the morning. The hospital has no facilities for disabled people and she feels she is being treated badly. She wants better facilities for disabled people who need psychiatric treatment.

SANELINE gives advice on changing GP's and offers to research local hospitals

Page 0000000000

Type of service: Request:

Name of service:

BRIEF DESCRIPTION: 1) Mutual Support Group for those with mental health problem
2) Self-help Resource Centre offering info on mental health problems.
3) Refracting Scheme offering social/recreational support to individuals.

HOW TO ACCESS: Telephone for details.

Street: London Area:

District or Town: City:

County: Postcode:

Contact (1): Phone (1):

Contact (2): Phone (2):

Position: Time to call:

Area:

14-0000000000 04-7-0000000000 0000000000 11-21-00

SANELINE INFORMATION DATABASE Page 0000000000

- anti-psychotic medication widely used in schizophrenia and hypomania.
- used in smaller dosages for short-term treatment of anxiety.
- Tablets (Haldol, Sereace) initially 1.5-20 mg daily, increasing as required to maximum 200 mg daily.
- Usual minimum dosage is 3-10 mg daily.
- Injections: for emergency control of over-excitability or agitation.
- Depot injections (Haldol Decanoate) 50-200 mg every 4 weeks.
- symptoms of dystonia, akathisia.
- nausea, loss of appetite, indigestion.
- sedation and loss of alertness.
- weight gain in some cases.

14-0000000000 04-7-0000000000 0000000000 11-21-00

(Far left) One of the 100 volunteers who keep SANELINE open every day of the year from 2 pm to midnight. Volunteers receive a minimum 35 hours training. In front of her, is the database screen which provides information

(Left and centre left) Examples of what the volunteer sees on the screen. A local entry for a sufferers' support centre in the town of Dundee includes a description of the help it can offer. The entry for the drug haloperidol explains its uses, doses and side effects.

(Below left) Volunteers in training. A secret of SANELINE's success is the quality of the training they receive.



for help

He was discharged from hospital, where he had been treated compulsorily, a week before Christmas. His parents are abroad and no one else takes any interest in him. "I don't want to involve the police," says Joe. "They've been around already and can't do a thing to help." Alan is not an immediate danger to anyone - however, Joe is afraid for his family and other neighbours, as well as being concerned about the dreadful living conditions Alan has been living in.

SANELINE gives Joe numbers for emergency social services, a mental health resources group and the local reach-out team.

2.30pm A police officer rings from a village in the north of England after being called out by the husband of a woman who had attacked him with a knife. The husband begged the officer to help him get treatment for his wife as the GP refused to come unless the wife asked for him herself.

SANELINE suggests the husband approach an approved social worker for an assessment under the Mental Health Act for his wife.

6.20pm Mrs Bell rang to talk about her daughter, Irene, who has suffered from schizophrenia for seven years. She refuses to take her medication because she says she gets so little help from the social services or her GP. She has been arrested for shoplifting. She lives alone and drinks a lot to 'take away the pain.'

SANELINE puts her in touch with a mental health support team she has not previously contacted.

8.45pm A 60-year-old woman living on her own calls. Her son, 27, was detained in hospital a month ago for

a "macabre" self-injury. She has received little helpful communication from the doctors, and has been told that her son will soon be discharged and that he should come and live with her. She is now terrified, because her son has often threatened to kill her and himself.

The SANELINE volunteer put her in touch with a legal adviser.

11.30pm A distressed young woman rings sobbing from a telephone box. She tells the volunteer she has a lot of pills and has already taken some. Just before her money runs out the volunteer manages to get her number and ring her back. The woman says she has been discharged from hospital and has nowhere to spend the night.

The volunteer summons the paid co-ordinator who is always on duty. She arranges a bed in a women's refuge while the volunteer continues to reassure the distressed caller. However, after talking for an hour the woman's voice becomes slurred. Eventually she admits she has taken all the pills.

The SANELINE co-ordinator rings emergency services and talks to the ambulance driver while the volunteer does her best to keep the woman conscious.

Midnight Just as the shift is about to go home, Sandy rings from Cardiff. She is a regular caller. Tonight voices in her head are shouting and abusing her and she is unable to sleep. She is terrified.

Her story is well known to the SANELINE volunteer, who has often talked her down, reassuring her that the voices do not need to be obeyed. After 10 minutes, Sandy says she feels better and will put on her Walkman and try to sleep.

A YEAR IN THE LIFE OF SANE'S BOOMING BABY

SANELINE opened on 29 April 1992 and was an immediate runaway success. CARYL WRIGHT and HAZEL KEELAN describe its precocious first year

Such has been the demand for SANELINE, it often seemed in that first year like being in a small boat in a stormy sea about to be swamped. On the first day the lines went mad: 180 calls were answered and each time the number appeared on television there was a tidal wave. If things went on like this, we had too few lines and volunteers to take the calls.

Finding lines was simple, but it was harder to find and train more volunteers. The struggle has gone on ever since.

In our first year we handled over 71,000 calls and, sadly, another 30,000 people found the lines engaged. We are doing what we can to reduce that, but it is impossible to ride every wave.

Volunteers

Calls at SANELINE are taken by trained volunteers who make a commitment to work at least three 4 hour shifts every month. Each shift is supervised by a paid co-ordinator, of whom there are seven. Some are trained counsellors, others have experience of working with the mentally ill. All have been Samaritans. Co-ordinators also run the training courses.

SANELINE volunteers come from all walks of life and vary in age from 20 to 72. They are selected for their warm and sympathetic manner, and while no specific qualifications are required, an interest in mental health issues is useful. The first group of volunteers trained were mostly carers, with a family member suffering from schizophrenia.

There are also some mental health professionals, students, retired people, and more recently, recruits have tended to be young professional people with no direct links with mental illness. The training they undergo in groups of 20 consists of 35 hours spread over 6 weeks, including 3 Saturdays; they have lectures from a Psychiatrist, an Approved Social Worker, a Legal expert, a Community Psychiatric Nurse, and they role play calls aiming to help them develop listening skills and learn how

to support someone in a crisis. Potential volunteers also spend several hours learning to use SANELINE's database.

The Database

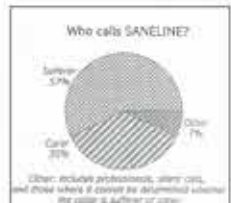
The database forms a vital part in the way SANELINE helps callers. It contains over 10,000 entries of local mental health services, support groups, counselling centres, etc, all indexed and linked to the nearest town. It was designed to be very simple to use, even when holding a telephone. Volunteers who swore never to touch a computer have mastered it! The database also has information on treatments and medication, the Mental Health Act and many other subjects.

A caller in a remote Norfolk village with a son suffering from schizophrenia the nearest Family Support group, or explain the role of the Approved Social Worker, the side effects of Largactil, or the purpose of the Mental Health Review Tribunal.

All information is updated every 6 months, and callers are encouraged to ring back to keep SANELINE informed about the service they have received.

Who Calls?

A rather stable pattern of people who use SANELINE was established over the first year. We had expected most callers to be family carers and were surprised that more than 50% were



sufferers, most of whom showed themselves very much aware of their position and their problems and even knew the names and doses of the various drugs they had been prescribed.

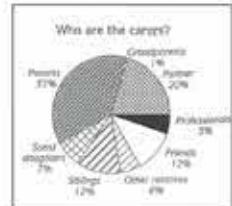
More women telephoned SANELINE than men: three quarters of carers were women, and 60% of sufferers,

The volunteers write a detailed (but confidential) log about every call they take, and we have been analysing these to see how callers cope with mental illness, what their problems are, and the treatment they receive from health care services. Some of the findings are worrying.

Nearly half the callers talked of the unmet need of the sufferer for medical treatment, including lack of information on the side effects of prescribed medication, and lack of consultation or discussion of the need for psychological treatment or counselling.

One in every five said the sufferer's failure to take the medicines he had been prescribed meant his illness was not properly controlled and resulted in severe disruption to family life.

More than a third of all callers, had problems with the sufferer's behaviour, usually violence, aggression, anti-social and bizarre behaviour. In four fifths of these unacceptable behaviour was causing family relationships to disintegrate. One caller in five was worried

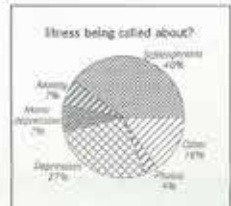


about negative symptoms of the sufferer: lack of motivation, inability to cope and self-neglect.

One caller in five mentions suicidal thoughts of the sufferer, and of these more than half have actually attempted suicide at least once. About one person in ten of those who mention suicide are in the process of carrying it out when they telephone. We have had many dramatic calls in which the SANELINE volunteer has been able to 'talk-down' the caller, sometimes after he or she has taken an overdose, so that an ambulance must be called.

We have also analysed callers' comments on statu-

tory services following the implementation of the Community Care Act in May 1993. Nearly half of those questioned were dissatisfied with the care received from general practitioners, and one in three criticised the treatment received from psychiatrists.



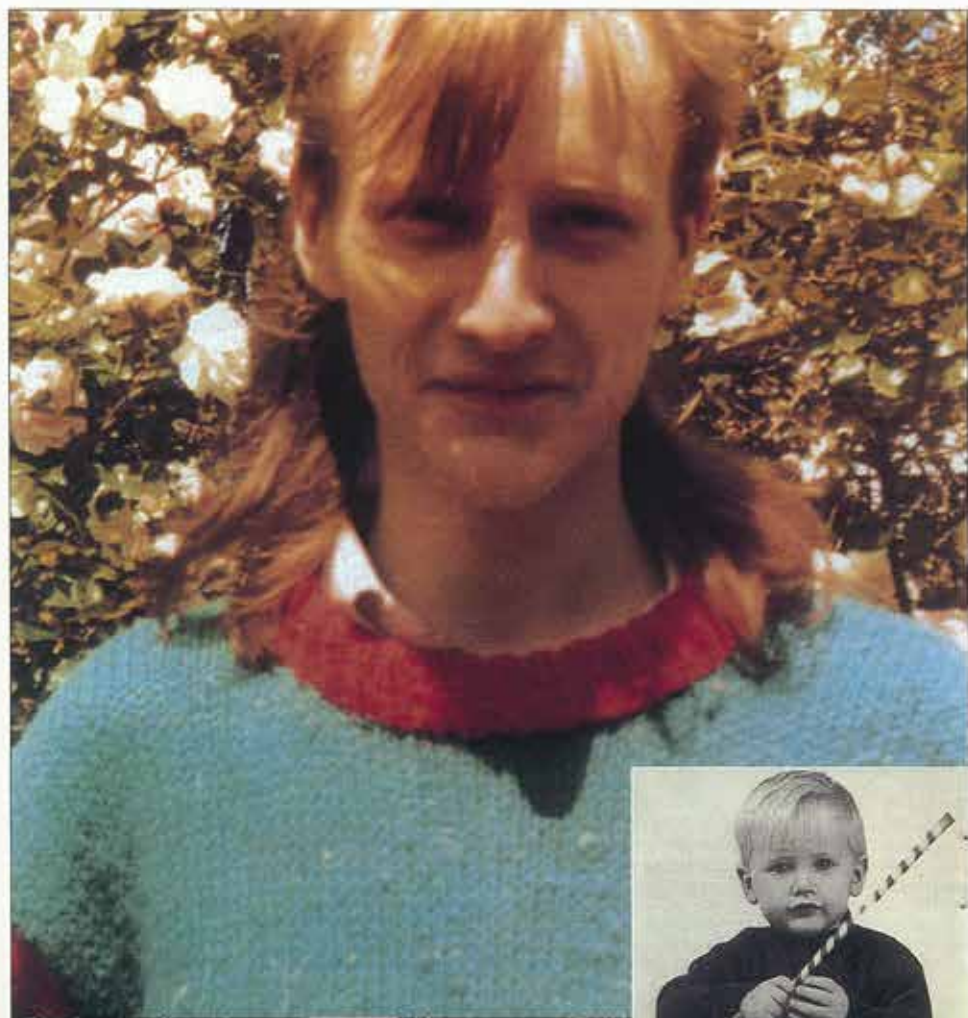
The Future

The first year was really a remarkable success for SANELINE, demonstrating the need for the service, and the potential use of log sheets as a social research tool, without compromising the confidentiality of the individual caller.

In the future we hope to make SANELINE available to more people both by extending the opening hours (currently they are 2.00 pm to midnight every day of the year) and by providing more lines and more volunteers to meet the growing need.

We expect to develop a national network of outreach workers and new services. Our aim is to provide the best possible information, and to open up as many options as possible to give new hope and determination to people coping with mental illness who may feel unable to go on.

And we intend to improve still further the information service provided by the SANELINE database, partly through feedback provided by callers. We are already beginning to build up within the database a pattern of the areas of the country where services and resources are available and working well, and where there are problems. Hopefully the data we obtain from the analysis of callers' needs and problems will help to improve the quality of mental health services as a whole.



Edward Curtis-Bennett fell ill, ill enough to kill himself. His family pleaded for him to be detained compulsorily in hospital; the hospitals refused. Individual freedom is today considered to be more important, even if it means, as it has for hundreds of mentally ill people, the right to die. Should he have been given that liberty? Or should society have taken control? Whose mind is it?

DID EDWARD HAVE TO DIE?

Report by Marjorie Wallace

From *The Sunday Times Magazine*, 24 July 1988

It was seven o'clock in the morning this Maundy Thursday when Fiona Taylor, a young post girl, drove her van down a country lane near the market town of Castle Cary.

She pulled up at the entrance to a track leading to two cottages whose grey slabs rub pleasantly against the rich turf of the Somerset hills. The distant sight of the cottages and cows grazing the pastures was as idyllic as it was familiar. She was quite unprepared for what she saw next.

In a dip in the lane a red MGB GT was parked with its engine still running. As she walked towards it she noticed a length of green hose leading from the exhaust into the window of the passenger seat; she opened the door and saw the body of a young man whom she recognised as the son of the woman who lived in the first cottage.

Edward Curtis-Bennett was 22 years old when he took his own life. He had spent the night at home while on

(Top) Edward Curtis-Bennett at 19 before illness struck and (centre) as a child of 20 months

(Left) Elizabeth Grant, his mother, in her garden overlooking the lane where Edward's body was found

leave from hospital, driven his mother's car around the countryside and parked it in the lane. There, as night faded, he took his final steps.

At first sight it would seem a straight-forward case of suicide while suffering from mental illness.

But behind his death lies a complex drama of a gentle young man whose mind was possessed by schizophrenia, one of the most cruel illnesses known to man; his mother who lived like a fugitive for three years; and a society which stood by and waited for the inevitable.

Edward was a bright, charming and inquisitive child. He was the son of Elizabeth Grant (a cousin of the Bloomsbury artist Duncan Grant) and the late Paul Curtis-Bennett, a flamboyant and well-connected lawyer. Elizabeth had two daughters and a son by a previous marriage. Both daughters are now married and her son is a vicar in the Midlands.

Edward's childhood was not altogether conventional. He and his mother would spend months away in the country while his father led a busy social life in town and when Edward was six his parents separated. He seemed happy enough. At school he spent many hours gazing out of the window

and failed to achieve academic success, but he was intelligent and acute.

"His developing concern for the human condition will be of great value to him in future life," one school report says. "His written English essays show at times a high degree of perception and observation..." wrote his English master. Sadly, it was just these qualities which made his later torments intolerable.

The change in his personality was sudden. One day in January 1985, when he was 19 years old, Edward came downstairs and watched his mother eating lunch. It was a bleak day and the lane leading to their cottage was buried in snow. Without warning, he overturned the kitchen table. Then he cornered his mother with a chair at her neck and held her transfixed for the next two hours.

"He just stared at me with murder in his eyes," says Elizabeth. "There was no way I could escape." Eventually, he put the chair down and she went upstairs to pack for a business studies course which she was attending the next day. But he followed her up the narrow stairs and lay on the landing outside the bedroom door, an iron bar in his hands.

Elizabeth could not believe that this enraged terrorist was her son: "He told me that if I moved, he would hit me. All I could do was to try and will good thoughts into his head," she recalls. "It was my only form of defence. But he glared at me for a long time and said: 'You look evil.'"

When she eventually risked moving, he hit her across the back and arms with the bar. Then he pushed her down the stairs and threw her out into the snow, locking the door. When he opened it an hour or so later, she found him sitting by the telephone with an electric cable tied in the shape of a noose.

"I had seen him occasionally in a temper, but he had never shown violence and certainly not insane violence on this scale," she says.

Edward's rage evaporated and Elizabeth left the cottage. She visited her GP, told him about the attack and was referred to a psychiatrist at Yeovil General Hospital. It was her first taste of the casual way such family dramas are viewed - an experience echoed by hundreds of other relatives in distress in Britain and other countries who find that when they need help, the professionals have no time, powers or motivation to intervene.

"Edward was told to structure his life more carefully," she says. "The doctor suggested he did things like drumming practice every day and if he failed to discipline himself, he should join the army."

Edward's disturbance was more profound than lack of self-control. He would deny there was anything the matter with him, yet at the same time he placed an advertisement for help in the personal column of *The Times*. One afternoon, Elizabeth was listening to a programme

about schizophrenia on Woman's Hour. Edward came in. "Does it remind you of anyone?" he said.

Schizophrenia is, in fact, a common disease. It attacks one in a hundred, mainly young people in their teens or early twenties. The onset may be sudden and acute: the person hears voices, sees visions or believes people are trying to kill him. Or it may be more insidious, causing him to lose his drive, become withdrawn from friends, stay in bed all day and pace about the house by night. It is probably due to a chemical imbalance in the brain, triggered by stress, and there is evidence of some genetic vulnerability.

A third of the patients recover completely from the breakdown; a third go on to live through cycles of mental torment for the rest of their lives, but with periods of relative calm; the rest never recover. There is no known cure, but the worst symptoms can be controlled by drugs such as Largactil.

Elizabeth bought Edward a caravan and parked it in a field a few miles away from the cottage. He agreed to live there and she would walk across the fields to bring him clothes and food. He became more withdrawn, spending his days alone, tinkering with his motor-bike.

By winter, he had returned home but his behaviour had become even more strange. "He was trying to find the eternal verticles," said his mother. "He would ask me why he had been born and the meaning of life, and when I couldn't answer he'd become so frustrated he'd break the furniture or windows or snap the blades of kitchen knives."

Elizabeth began to live on the run, seeking refuge with friends, torn between her fear of staying with him and

"He would ask me why he had been born and the meaning of life. When I couldn't answer he'd break the furniture or snap the blades of kitchen knives"

the worse fear of how much he suffered when alone.

Just over a year after his first attack on his mother, Edward knocked her down and kicked her in the face. Elizabeth drove to the police, who were sympathetic but had no powers to help beyond suggesting that she take out charges against her son. "It was not a thing I could do," she says.

In February 1987, Edward was seen by Dr Jonathan Cohen, a young consultant at Yeovil General Hospital, who occasionally sports a bomber jacket, rides a motor-bike and has a reputation for getting on well with young people. "I thought Edward was strange but I



Dr Jonathan Cohen (above), consultant psychiatrist at Yeovil General Hospital. "I'd have prevented Edward's death by locking him up. But you can't put a ball and chain on everybody"

did not think he suffered from schizophrenia," says Dr Cohen. "I tried very hard but he was not interested in talking to me or in my field of medicine. I have to rely greatly on what people tell me and Edward would say very little. He did not appear to want my friendship or doctorship."

So mother and son were left alone to struggle against the encroaching shadows on Edward's mind. He began to neglect his appearance, his thoughts became more disordered and his behaviour more bizarre. Elizabeth felt increasingly unsafe in his presence. Once, when she wedged her bedroom door at night, he tried to break it down.

"I didn't know where to turn," says Elizabeth. "I'd been to the doctor, the psychiatrist, the police and written to the social worker. I was given tranquillisers but there was no help for him."

For the next eight months she wrote letters to doctors describing his state of mind, but no one was prepared to intervene. In October 1987 Edward attacked her for a third time and she fled the cottage, not returning for a month. During her absence she got Dr Cohen and the GP to visit Edward but they found him listening to music and talking coherently. "He was drinking a lot and had bizarre ideas relating to sex, driving fast motor-bikes, and drugs... I asked him to attend my patient clinic the following week... He did not attend," says Dr Cohen.

It seems extraordinary to expect someone like Edward to take himself to a clinic. For the paradox is that mental illness drains the will and distorts a person's judgement: the more disturbed he is, the less able he is to seek help or keep appointments.

Elizabeth wrote to Dr Cohen again and received this reply: "I regret to inform you that your son failed to attend for my appointment and since I am a busy man I cannot afford to send him another if he continues to stay away... I am sorry I have not been able to help you as we would have liked, but I can only treat patients that I see; if I do not see them I cannot treat them!"

So far has the pendulum swung in assuring the rights of an individual, however disturbed, not to have treat-

ment unless he seeks it and so biased have many doctors and social workers become against the relatives, particularly the mother who is often tacitly held to blame for her child's condition, that nothing is done which could be said to infringe a patient's liberty.

This approach is much influenced by the heady reforms of the Sixties, when the civil liberties movement was at its most vocal and freedom, whatever the cost, was the cry of the day. Reforms were already under way with the discovery in the fifties of drugs which controlled the worst symptoms of mental illness. There were also exposés of conditions in Victorian-style asylums. Wards were unlocked, bars removed, and most of the patients were free to come and go. The emphasis on safeguarding individual liberty later became mixed with other notions sweeping the United States and Europe; that by treating everyone as normal, they would become normal, that mental illness is not a medical condition but a reflection of wrong expectations in society especially of parents who literally "drive" their children mad.

The damage caused by these muddled philosophies, based on unproven research and tiny samples often unrelated to people with severe mental illness, has been devastating. Not only have they influenced the government policy to close down asylums at a rate far out-

The paradox is that mental illness drains the will and distorts a person's judgement: the more disturbed he is the less able he is to seek help or keep appointments.

stripping the provision of care elsewhere, but they have seeped into the attitudes of doctors, nurses and social workers, encouraging their suspicions of parents and placing all the emphasis on the rights of the patient.

Professor Julian Leff of the Maudsley in South London, one of Britain's leading psychiatric hospitals, believes that "in practice my colleagues are leaning over backwards to avoid bringing people into hospital because of the worry about the civil rights issue".

"They seemed to think I was a twitting idiot," says Elizabeth. "It makes you feel particularly helpless when you're not believed."

The aim of treatment is to make everyone independent, whether or not they want to be - or indeed can cope. Priority is given to people with treatable, acute illness. Long-term problems such as chronic schizophrenia or a "personality disorder" are managed outside. At best sufferers live in a range of accommodation which varies from flatlets, staffed small units and group homes to private bed-and-breakfasts and dismal lodgings. In most cases, however, such as Edward's, "community care" is simply a euphemism for home.

Families are expected to succeed where skilled nurses and doctors have failed. Sometimes they are offered the support of a "multi-disciplinary team", which often means a fortnightly visit from a community psychiatric nurse or social worker whose aim

"I am sorry I have not been able to help you as we would have liked, but I can only treat patients that I can see; if I do not see them, I cannot treat them!"

seems to be to prevent costly hospital admission.

By the beginning of this year, the stage was set for the final act. Mother and son were still locked in the impossible struggle against his disintegrating mind. The rest of society stood by like a Greek chorus commenting on their fate. Edward had developed delusions which reduced him to a state of terror; he was convinced the police were able to beam in on his thoughts and he believed that a gang of Hell's Angels were out to murder him. "I would find him sobbing on the floor with terror or barricading the door, panic-stricken," says Elizabeth. "He couldn't dissociate what was in his head from reality."

She tried to cheer him up by taking him on outings. They went on one picnic to the hills near Shaftesbury where he had flown kites as a child. The sun shone and for a while he was carefree and happy. But on the way home a cloud descended on his brain. "He began to scream and scream. He looked very ill, like an old man," she recalls.

At this stage, Edward too had moments when he seemed to realise he was gravely ill. He telephoned the Samaritans on two occasions, spent the night in

the under-pass in Yeovil and finally, on March 2, dialled 999 and claimed the police had stolen his thoughts. He asked to be put in hospital compulsorily, but Dr Cohen felt that he was not a sufficient danger to himself or others.

Since the 1985 reforms of the Mental Health Act, it has become more difficult to detain a person compulsorily "under section". But Professor Leff believes the question is one of interpretation: "The Act allows you to take someone into hospital against their will for the sake of their own health. The Department of Health's recommendations are that treatment can consist of not only the cure of an illness, but also enabling the person to better cope with the symptoms arising from their illness. It appears to me that a number of my colleagues are not using the Act in that spirit..."

Psychiatrists differ on the interpretation of the Act. For Dr Cohen, taking away a person's liberty is serious and often counter-productive in therapy. "There was no reason to detain Edward at this point," he told the coroner. "In Edward's case, as in others, the treatment is not just within the hospital environment but also within the community... It is important that you don't put them under lock and key but try and integrate them with normal people. One of the features of this disorder is that they feel different from others and if you treat them differently it just reinforces that feeling." That is a terrible dilemma for any doctor.

Edward was admitted as a voluntary patient and was finally diagnosed as suffering from schizophrenia.

On the third night, Edward discharged himself and went missing for two days. He returned to the hospital but the following week he again discharged himself. Despite having taken anti-psychotic drugs, he raced on his motorbike up the motorway to London. He went to St Charles Hospital in West London, where he asked for "sanctuary" and again begged that he should be compulsorily detained. He also rang his half-sister, Julia de Nahlik, who lives in London. She visited him there.

"I was horrified by how much he had deteriorated. He looked so terribly drawn, his skin looked so tight and he had scary eyes," she says. "He'd dyed his hair black and cut out huge chunks. He said the police had made him do it."

She asked the doctors at St Charles to keep him under section but, like the doctors at Yeovil, they refused. "They told me it was a serious thing to restrict someone's liberty."

Still medicated, Edward discharged himself from St Charles and returned to Yeovil. He knocked on the window of a local police-woman who had been friendly to him in the past. WPC Beaton was shocked by his appearance. "He told me that he was desperate, that he didn't know whom to

turn to and asked me if I could get him confined in hospital," she says. "He said that if he were free to walk out he would end up killing himself - or somebody else. He was too gentle to harm anyone. I believed he would take his own life."

The team in the psychiatric wing of Yeovil General did not want to detain him, and, after some difficulty, Edward was re-admitted as a voluntary patient. He was allowed out, sometimes with escorts but at other times on his own.

Ten days later, Edward visited his mother at home and attempted to gas himself in a Dormobile van. Elizabeth told the hospital about this, and about his constant pleas to be detained.

At the inquest Dr Cohen denied that there was any record of this report. "I did not think there was a high risk of Edward committing suicide," he said. "He did not give me that impression."

By now the whole family was becoming alarmed about the safety of their mother and half-brother. Edward's brother-in-law telephoned the hospital, asking that he should be detained. So did his half-brother, the vicar. On March 29, Julia and her sister Victoria visited Dr Cohen and told him their fears. "We said it was especially important that he should not be allowed to go out with my mother," says Julia. No notes were taken of this meeting and no messages passed to members of the staff.

The next day Edward was allowed to visit his mother at home. She was not alarmed. In the last months, despite his deepening paranoia and threats of suicide, Edward had become more like the affectionate and sensitive

nightmares. It was the last time she saw him alive.

Edward had exercised his final right - the right to die. There are no statistics on how many people suffering from schizophrenia commit suicide, but it has been estimated to be one in 10. There have been at least 13 cases during the past 18 months in the area where Edward lived, many of them while the patient was unsupervised away from the hospital, often at home.

"Suicide and death are a part and parcel of medical care," says Dr Hugh Koch, a general administrator for Somerset mental health services. "In psychiatric treatment there is a small percentage of people in any catchment area who, with the best will in the world and with care and support for them and their families, will end up killing themselves."

Suicide is indeed a part of everyday experience for any family where there is a victim of schizophrenia. These families tell the same, desperate stories. The parents clutch files with dismissive letters from hospitals, broken appointments from out-patients and notes from social workers dropped through the door.

Little protection is offered to mothers like Elizabeth Grant or Jane Briggs, a farmer's wife, who lives in constant fear of her son. "If he tells us he's coming," she says, "I rush round and hide all the knives and dismantle the farm gun."

According to Dr Koch, these difficulties should be taken in everyone's stride. "Aggression is not in itself an excuse for detaining. There is no evidence to support the view that there is more aggressive behaviour among psychiatric patients towards their families than in the general population."

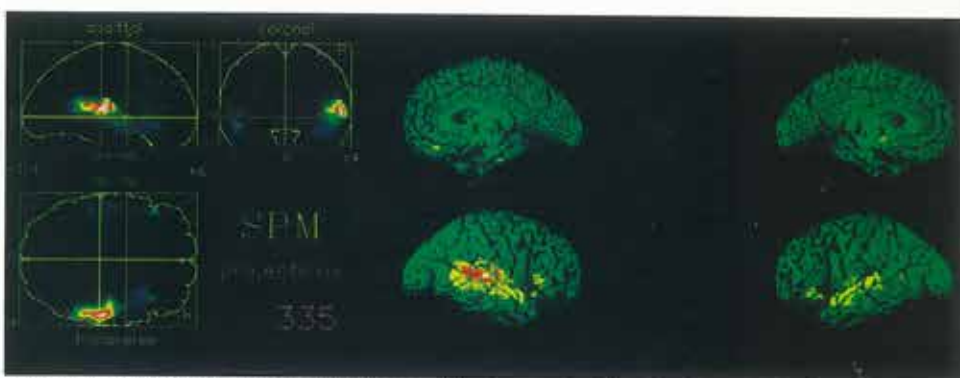
Doctors like Dr Cohen are juggling with impossibilities: on the one hand a society which says that people, however ill, must be free and, on the other, families and sufferers for whom that freedom may mean death.

Edward's case, says Dr Cohen, "was a tragedy, but I cannot predict the eventual behaviour of all my patients. That's impossible. I'd have prevented his death by locking him up. But at that time the evidence showed he was not at risk."

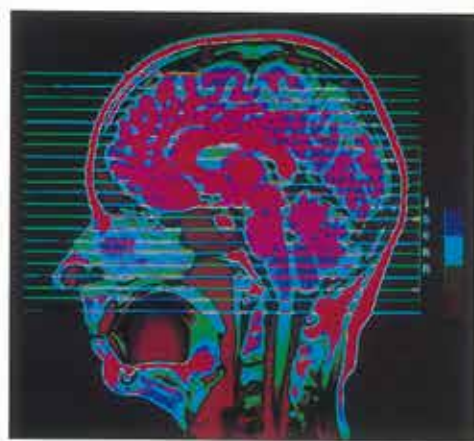
Should Edward have been given his physical freedom when his mind was imprisoned by delusions? Elizabeth Grant resents the implication that, with such a crippling illness, the only way out is the one her son decided to take.

At his memorial service, she chose a poem by an anonymous American:

"I have seen death too often to believe in death. It is not an ending, but a withdrawal. As one who finishes a long journey, Still the motor, turns off the lights, Steps from his car, And walks up the path to the home that awaits him."



One of the most exciting new technologies is the PET scan which shows up parts of the brain which are active. Scans like this can show up brain activity as a sufferer hears 'voices'



(Above). Magnetic resonance imaging (MRI) gives superbly detailed pictures of the structure of the brain, but it cannot give the snapshot effect of the PET scan. These and other new methods of looking into the brain are important research tools

(Left) As part of its research work SANE already supports a library containing the 'immortalised' cells from families that show strong inherited risk of schizophrenia

Doctors like Dr Cohen are juggling with impossibilities: on the one hand a society which says that people, however ill, must be free and, on the other, families and sufferers for whom that freedom may mean death.

son he had been before the onset of his schizophrenia. The love between them seemed to have fresh life and hope. But that evening he refused to return to the hospital. "He rang up and said he was not coming back," Elizabeth remembers. "They said that it was fine for him to stay the night if it was all right by me. I took the phone and said I did not agree." The hospital say that they have no record of her contacting them, and therefore took no action.

No one came to fetch him. He went to bed and later came downstairs telling her he had been plagued by

HUNTING THE ELUSIVE CAUSE OF SCHIZOPHRENIA

How are we to lay this rogue disease, which breaks all the rules and reveals itself mainly through the havoc it creates in the minds of its sufferers? DR TIMOTHY CROW, unstintingly creative Director of the MRC's Clinical Research Centre, Division of Psychiatry, returns to first principles, looks again at the essential features of what might cause schizophrenia and points a finger towards new possibilities.

Reproduced from SANETALK, June 1992

THE DIFFICULTY of understanding the nature of schizophrenia is that it is a disease for which few comparisons are possible. It is common, has an onset in early adult life, and causes chronic disability. It is also associated with decreased fertility, particularly in males. These characteristics mark it off from most if not all physical diseases. Where these have a genetic component and are common, they generally have an age of onset late in life, and therefore do not reduce fertility. When they occur early they are rare, and the genetic component is often recessive, i.e. the gene is inherited from both parents. Perhaps the closest analogy is manic-depressive illness, a

disease whose origins are as obscure, but which shares many characteristics with schizophrenia. Manic-depressive illness is at least as prevalent, although it generally occurs at a later age, and there is an overlap in symptoms between the two conditions. Indeed the occurrence and frequency of intermediate states (i.e. illnesses with both schizophrenic and manic-depressive symptoms) suggest strongly to me that the two conditions are aspects of a single problem. A solution to one aspect may require consideration of the other. Illnesses of high prevalence can be due to environmental causes. Infectious diseases are an example. But

schizophrenia has epidemiological features which are shared by no infectious disease. The conclusions of the World Health Organisation ten-country study are salutary: "schizophrenic illnesses are ubiquitous, appear with similar incidence in different cultures, and have clinical features that are more remarkable by their similarity across cultures than by their difference." (Psychological Medicine Supplement 20, 1992). A number of environmental factors (viruses, toxins and allergens) have at one time or another been suggested as causes of schizophrenia, but few if any specific proposals remain as serious candidates. What en-

vironmental agent can one suggest that would not vary substantially across the globe? What factor would remain constant across wide variations in climate, industrial and social structure, so as to affect a relatively constant proportion of individuals, and those in a particular phase of life? Two further findings are relevant to the gene versus environment controversy. First, when illness occurs in two children of the same parents (which it not infrequently does), it does not happen at the same time, as with diseases caused by a common environmental factor, but as each child reaches the same age. Secondly, being adopted

away in early childhood from a family in which there is already a member who suffers from schizophrenia, does not reduce the risk that the adopted child will develop the disease.

Both findings suggest that environmental factors, at least those that occur in post-natal life have little influence on the onset of schizophrenia.

The possibility remains that some outside influence that impinges on the individual in foetal life or at the time of birth, in some way predisposes that individual to schizophrenic illness 20 or more years later. Two such factors have been suggested: influenza in the mother in the second trimester (4th to 6th month of pregnancy); and complications, such as hypoxia or head injuries, occurring at the time of birth.

Both possibilities have been examined in a sample of 17,000 individuals whose

"Environmental factors have little influence"

births in a single week in 1958 have been carefully documented (the British Perinatal Mortality Survey and the National Child Development Study). We identified subjects who were later admitted to psychiatric units. Those who were diagnosed as suffering from schizophrenia were no more likely than the rest of the population to have had birth complications. Nor were their mothers more likely to have suffered from influenza in the second trimester, a finding which acquires cogency from the fact that these mothers were at risk of influenza in the epidemic that occurred in Autumn 1957.

If the general case for an environmental cause is weak, and if such specific candidates as were presented have been eliminated, one must return to the difficulties of the genetic theory.

How can a disease that is genetic have an outset in adult life? Why is it that the majority of cases (perhaps 80 per cent) have no family history of illness? Why is the schizophrenia gene (if such a thing exists) not eliminated from the population if it is associated with such a decrease in fertility?

Perhaps we can begin to see an answer to some of these questions in recent studies. The outline we see is part of a picture that is wider than the problem of schizophrenia.

Studies of brain structure reveal consistent but subtle differences between people with schizophrenia and others.

These differences include some which relate to that area in the posterior part of the temporal lobe that is concerned with the reception and analysis of language. It is the part of the human brain that is most asymmetrical and it may well be the most recently evolved.

Family studies have shown that among the relatives of patients with schizo-

phrenia there are some who, while not themselves experiencing the more typical features of the illness, such as hallucinations, do share certain personality characteristics with sufferers. For example, they may show some withdrawal from social contacts. Similarly, the relatives of patients with manic-depressive illness, have a greater tendency to mood swings than others.

There is, of course, a whole range of behaviour which, although different, is regarded as normal. So the question arises whether we are dealing with discrete illnesses, or whether those who are "ill" merely lie at the extremities of the distribution of the normal (and perhaps socially very important) differences in personality between individuals. What this approach can not explain is the nature of the psychotic symptoms, or their periodicity.

Another interesting set of studies show that people with schizophrenia (especially males) are quite often noted by parents or teachers to be unusual in certain ways years before the onset of their illness. Some had academic difficulties, including language comprehension and use, and some experienced social problems. We do not yet know what proportion of those who develop schizophrenic illness showed such problems earlier in life. Such deviations suggest that the genes that are later associated with the expression of psy-

"Human society depends on communication"

chosis are related to the human capacity to interact and communicate with others. Taking a broad diagnostic view, one can see some possible advantages of the genes that are associated with psychosis and the significance of the neural mechanism they control. The psychologist, Kay Jamison, has pointed



Since he wrote this article, Dr Tim Crow, one of Britain's most eminent psychiatrists and brain scientists, has become Scientific Director Designate of the Prince of Wales International Centre. He is currently Head of Psychiatry at the Medical Research Council's Clinical Research Centre, London. He has received many international honours, including US NARSAD's Lieber Prize and the Research Prize of the World Federation of Societies of Biological Psychiatry.

out how common manic-depressive illness is among creative people in many fields. Some of them, such as Strindberg, van Gogh and Newton had illnesses which could well be described as schizophrenic. Noreik and Odegaard in Norway found that people employed in the professions were more than twice as likely as the general population to be admitted to a psychiatric unit with a diagnosis of manic-depression. Karlsson in Iceland found that the first degree relatives of those with all types of psychosis were slightly, but significantly more likely than the general population, to have graduated from university, to appear in the Icelandic Who's Who, or to be elected to Parliament.

So could it be that the gene or genes which are associated with psychosis are the ones that are concerned with variation between individuals; with the development of language and intelligence; and with the capacity for communication?

These are the genes which make us what we are; the human species; the species that combines a high degree of social organisation with large variations between individuals.

Ants and bees live in complex structured societies, gene driven with no room for breaking the rules.

But human society depends on flexibility of communication, learning and differences between individuals, and has evolved as an elaboration of these aspects of its primate origins.

How do these ideas stand up to our original objections to a genetic basis for schizophrenia?

The late onset of schizophrenia is explicable in terms of the functions of the genes. Language and communication are only fully developed in early adult life.

The absence of family history (in most cases) could be because the underlying genetic mechanisms are as-

The extremities of normal personality

sociated with a high degree of variation (perhaps related to an increased rate of mutation). This variation might be expressed in an additive form with the contribution of both parents summed.

In this way psychotic illness would represent an extremity on a continuum of variation that includes the non-psychotic population, rather than a mutated and defective allele of an otherwise normal gene.

We are left with the need to explain how the gene or genes persist in spite of the disadvantage of low fertility. But if the genes that cause the psychosis and low fertility, also maintain the diversity and flexibility of human communication, the very great advantage of those characteristics may ensure their survival. ●

SANE SELECTS CITY OF DREAMING SPIRES

Oxford University has been named as the preferred site for SANE's most ambitious project, the £4 million Prince of Wales International Centre for Research into Schizophrenia and Depression. Oxford was selected because, as MARJORIE WALLACE describes here, with more than 300 brain scientists, it provides an exciting research environment for understanding the causes of mental illness.

Reproduced from SANETALK, January 1993

When in May 1991, HRH The Prince of Wales launched the £6 million SANE Appeal, he said: "Leading scientists and doctors are confident the stage is now set for the great leap in imagination which could, in a few years, reveal the origin of this cruel affliction."

Today, nearly 18 months later that prediction is even more true. Brain research is as exciting in the 1990s as was space research in the 1960s. We are at the frontiers of important revelations on how the brain works. To secure more support for the research, the United States Congress designated the 1990s as 'The Decade of the Brain'. In Brussels, a few weeks ago, the European Commission announced the 'European Decade of Brain Research'. The time is ripe to establish an international centre, the first of its kind in the world devoted to schizophrenia and depression.

The Prince of Wales 'great leap forward' can only take place if there is sufficient investment of talent and resources devoted to finding the underlying cause or causes, as yet unknown, of severe mental illness. Recent developments using powerful new techniques, such as brain-scanning, or those involved in molecular genetics, have created a buzz of excitement among brain researchers, and the belief that within five or ten years' time we will be able to apply this new knowledge to the specific problems of conditions such as schizophrenia.

What we do know is that the brain of someone with schizophrenia appears to be working in a subtly different way and this is sufficient to cause disturbance in his thoughts, perceptions and emotions. Sufferers from schizophrenia seem to see different dimensions to the world; and they are unable to tolerate stress in the same way as other people. It is as though they were living in houses with paper walls, where too much is seen and too much is heard. They have no insulation against the unpleasant and distressing part of life.

There is little point, however, in focusing solely on the symptoms they experience, the particular shadows on their wall. The challenge is to find out what has caused the fragility of their world in the first place, so that we can build up their

defences and enable them to filter the relevant from irrelevant stimuli and eventually lead normal lives.

Researchers therefore have to investigate brains of people who do not have these disturbing symptoms, to find out what is normal and how the rest of us manage to protect our brains from becoming overwhelmed. They need then to find what fault-line has occurred, creating this vulnerability. In doing so, scientists find themselves going increasingly back towards the time when the actual structure of the brain was developing before or soon after birth; influences at that time, such as a viral infection in the pregnant mother, or damage at birth might become clear only later in life. This fundamental disorganisation could be lying dormant until triggered, usually, in the case of schizophrenia in adolescence

when there are rapid changes in the bodies hormones, or new stresses and demands are made such as passing exams, finding jobs, developing relationships and resolving family conflicts.

Linked to this interest in environmental factors is the possibility that the schizophrenic brain may be the consequence of faulty genes, the complex chemical chains which control the 'blue print' for the whole brain and body. The genes may affect the brain structure itself causing early disorganisation, or may cause too little, too much or an irregular distribution of what we call the neurotransmitters, or brain messengers, which are essential for controlling the way a person sees, feels and responds to his environment.

Researchers have already identified genes involved in such illnesses as cystic fibrosis, some blood disorders and, more recently, asthma. Many scientists believe we will be able to supply the same model to identify the gene or genes responsible for some serious mental illness. Once these genes have been identified, researchers can look for ways of replacing defective ones. Schizophrenia could ultimately share in these advances.

Another linked approach is new methods of brain imaging, which allows researchers to see exactly what receptors in the brain are being affected by different chemicals, so that

medication becomes less of a 'shot in the dark', knocking out innocent armies of receptors in order to capture the alien few. Through these scanning methods we can actually see what is happening in living brains, and which parts of the brain are being targeted by different forms of chemical treatment.

For centuries, scientists have been chipping away at the barriers between our conscious selves and the workings of our brain. Through the different scanning techniques we have created new 'windows' onto the brain, so that we can actually see what is happening and compare the brain activities of a person with and without the symptoms of schizophrenia. Whereas before all we could hear was noise and chaos, now we can observe the busy playground of the brain; we can see what chemicals are active and passive, who is bullying whom, where the messages are being carried. And with this insight, we will be able to isolate the troublemakers, either by removing or replacing them. It is by studying in close proximity to scientists involved in these new powerful techniques and combining this with knowledge obtained from treating sufferers, and understanding their personal experiences that we may achieve the long sought breakthrough.

The Centre will also look at schizophrenia in an international context. Up to now, studies have shown that schizophrenia is a condition which is found in all countries, and believed to have the same incidence, approximately one in 100. Some surveys, however, have shown pockets of population which reveal a higher or lower incidence of schizophrenia. These differences have not yet been sufficiently examined. They provide essential clues to the different causes of schizophrenia or forms of schizophrenia (many people believe it is more than one illness), just as rates of cancer in different countries have provided clues to the cause of a particular form of this condition.

Through international links, researchers from the Prince of Wales International Centre could test various hypotheses and conduct studies in different and contrasting populations. ●



PAUL LOVELOCK

THE END GAME

One for June, one for Jennifer. Twenty-nine-year-old June Gibbons whispered the familiar chant of her childhood as she threw two red roses into the grave of her twin sister.

A wind blowing in from the Atlantic, at this western tip of Wales, chilled a moment of deceptive sunlight and sprayed earth into our eyes. We were a small group of mourners clutched on the hillside of Haverfordwest cemetery to bury Jennifer Gibbons, who had died unexpectedly and mysteriously on March 9. Aubrey Gibbons, an upright and charming former RAF corporal, still dazed by his daughter's death, put his arm around the remaining twin, Gloria, their mother, swept dust and tears from her eyes.

Behind the family, their heads bowed discreetly, were three escorts sent by the Home office for June Gibbons. Recently transferred to a secure unit in Wales on a six-month trial, she remains a patient of Broadmoor Special Hospital, detained indefinitely at Her Majesty's pleasure.

The first rose had blown off the coffin, but the second fell straight and secure over the brass name plaque on the coffin lid. The priest read out some verses from a poem, *Shadows*, written by Jennifer.

It seemed that even at the age of 18, when Jennifer wrote the poem, she had known the price she or her sister would pay for having been born at the same time as a human being identical with herself, without whom she could not survive and yet with whom she would be forever trapped in mutual jealousy and enslavement.

It was the extraordinary intensity of their relationship that seems to have led June and Jennifer Gibbons to take vows of silence and reject the outside world. From the age of three or four they refused to talk to their parents or their brother and sister. At school they were never heard to speak to a teacher or another pupil; they would sit mute and wooden, or follow each other in a strange "dead march".

All attempts to help at a special school failed, and by the time the pair reached 16 the authorities had washed their hands of them. It was then that they embarked on their turbulent adolescence, living only for each other, reaching out in clumsy, self-destructive ways to local American youths who seduced them and left them.

Abandoned, frightened of each other and alienated from the rest of the world, they set out on a five-week spree of vandalism and set fire to three empty buildings. This final act of desperation to draw attention to their plight led to the arrest, imprisonment and eventual commitment under the Mental Health Act to Broadmoor Special Hospital for an indefinite period of time.

I was in court when the



The Gibbons family originally came from Barbados. Aubrey joined the RAF, and the 'silent twins', seen here as babies were born when he was stationed in Aden

judge announced that sentence and when the nods of these two lost mute girls were taken as pleas of guilty. As a newspaper writer I had become interested in the strange story of the silent twins. I had visited their family and had been led to the twins' small room strewn with black dustbin bags full of possessions returned by the police. Their father handed me the bags and I took them back to London.

Inside there was an extraordinary collection of diaries, short stories, poems, drawings, even novels, one of which they had pooled their unemployment benefit to have published. There were reference books, dictionaries, classics, writing courses and even, ironically, a course on "The Art of Conversation".

My knowledge of their writing was what brought us together and stimulated them to talk to me. Contact at first seemed impossible, but once I mentioned the plot of her novel I saw June's eyes flickering, her mouth edging into some-thing resembling a smile. "Did you like it?" she asked suddenly.

During my visits to Broadmoor, June and Jennifer began to smuggle their diaries across to me; millions of words in microscopic handwriting which revealed the most haunting and powerful descriptions I have ever read of how two human beings could drive each other to the edges of sanity and beyond.

Angered by the severity of their sentence, they fought the system, undergoing the extremes of a reward-and-punishment regime. But the

system began to wear them down. They told me: "We are going to talk ourselves out of here." They began to look more to the city within than across the walls to those who lived outside, and started to speak to some fellow patients and staff members.

Other things were changing too. In 1988 Sir James Savile was dropped by the Home Office as though by parachute into Broadmoor to lead a task force introducing reforms and new contacts with the outside world. Rehabilitation became the key word; visits to the seaside, local pubs and cinemas were encouraged. Attitudes towards the mixing of men and women became more liberal.

For the twins, life inside became a perpetual social calendar, a compulsion to "do" the season: summer barbecues, winter dances, fashion shows, a succession of parties played to rules of etiquette and sexual mores which could have formed the backdrop to any Jane Austen novel. Romances smouldering under the disapproving looks of nurses and ward managers. Jealousies flared between the twins and the other women. June wrote in a letter to me in January 1995.

"We went to the Broadmoor parties... You name it: Hallowe'en parties, Guy Fawkes parties, Easter parties, Christmas parties, school parties. We are the best-looking black girls here... We had the reputation of love and leave them. We wrote undying love letters, dated, flirtd, kissed passionately, but never had sex for 10 long years. We are now celibate women."

After 11 years in Broadmoor the twins June and Jennifer Gibbons were released last month in the first step on the road to greater freedom. But within hours of their release Jennifer was dead. Marjorie Wallace tells the story of two troubled women who could live neither together nor apart. Had the twins made a pact that one should die to let the other live?

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Prince speaks out for SANE

Launching the £6 million SANE Appeal in April 1991 for SANELINE and the International Research Centre, HRH the Prince of Wales spoke of the 'forgotten illness'

I AM particularly encouraged to see so many influential people here today because it is worth having it drawn to our attention that schizophrenia is, in fact, the most damaging and widespread cause of mental illness among young people. It affects the essential happiness and fulfilment of hundreds of thousands of people, yet it remains one of those willingly forgotten, 'out of sight and out of mind' subjects. Mental illness is certainly not an easy topic of conversation. Most of us don't know how to react to the subject and we can become embarrassed, which leads to the inevitable jokes and evasions. But there is a world of



SANE's Patron,
HRH The Prince of Wales
KG, KT, GCB

difference between being considered a little eccentric because of your enthusiasms and beliefs and being seriously and desperately disturbed with a condition which destroys your mind, your whole being.

Physical disability, illness, accidents which break bones or upset the functions of the body are painful, yet can be overcome by strength of personality, good medical care and will-power. Schizophrenia is different: we are talking about an illness which changes the way people think, understand and perceive the world around them and relate to others – the very essence of their personality – so that they are isolated from all sources of comfort and reason. I believe we have to accept that accidents can happen to the mind as they can to the body and that consequences can sometimes be even more devastating.

Tragically, teenagers and young people are particularly vulnerable to this terrible disease. When the worst happens – when a son or daughter first develops schizophrenia – he or she drops out of school or university, becomes deluded, loses friends and jobs and lives under the tyranny of imaginary voices. A young mother may be unable to accept or love her baby, because of her delusions and hallucinations. Children turn to their parents, or husbands to their wives, begging for help, for release from a torture they cannot explain. When a physically healthy young man sobs in a corner because voices in his head tell him to kill himself, there is little sympathy and almost no-one to talk to. Mental pain spiritual pain – is most definitely not a subject for everyday conversation.

Mental illness, perhaps not surprisingly, has been shrouded in secrecy for generations, the subject of one of the most intractable taboos that remain in our society. Families did not often still do not – admit to having any member who is mentally ill. And because people still find it difficult to accept, little has been done to help sufferers and of course, their relatives.

A few years ago I became aware from Marjorie Wallace's articles in *The Times* that schizophrenia was indeed a hidden problem in our society and this was the start of the process that led me to agree to be Patron of SANE. There is no doubt that it is an unfashionable cause and that is partly why I feel it is so important. People whose minds are disturbed are not usually socially attractive, but if only we could find a cure to their inner anguish, what satisfaction that would give them; what relief to their families and friends.

The lack of awareness and knowledge of schizophrenia was perpetuated for generations by the policy of locking the mentally ill away in mental hospitals. Few people knew much about schizophrenia and few cared... but in recent years successive governments have followed a policy of developing services locally, now that better

treatments allow more people to be treated in the community. In many ways this must be considered an enlightened policy – if, (and of course, it's a big 'if') the necessary degree of care can be provided in the community. Sadly, this is not always the case.

But there are others, more severely damaged by schizophrenia, for whom living outside hospital is not always the answer. At best, they would be a burden on their family – unless and until the strain grew too great. But then what happens to them if no safe haven is available? At worst, they would have no choice but to sleep rough – forty per cent of those who do are mentally ill, or so it is estimated.

I know that this subject is surrounded by immense controversy and that there are groups who believe that the only criterion for success is keeping the patient in the community. But don't we have to ask ourselves whether the community can actually cope with the patient and whether the patient is able to cope in the community? Care in the community implies that the community takes responsibility for its most unfortunate members. As a concept it is impossible to dispute. But we must, I believe, accept that in some cases community care on its own is not the answer – for any of the people directly involved, whether they are the sufferers, the carers, or the confused and often distraught families. Communities which do not understand mental illness and are frightened by it, cannot be expected to have all the answers.

I believe that there always will be, as there always have been, people whose single overriding need is for security and protection; for somewhere that will provide a sanctuary; a secure place of refuge and shelter. This doesn't necessarily mean putting people in hospital, but it does mean providing some sort of immediate haven where the person can be treated and freed from immediate pressures.

There is obviously a growing requirement to explain that the odd and

sometimes anti-social behaviour of people suffering from schizophrenia is the result of an illness like cancer or diabetes and is not necessarily anyone's fault. Coupled with this, there is a pressing need for support for those who are facing schizophrenia, in themselves, their families or their friends, and who do not know where to turn for help.

It is a normal human reaction when we don't understand something, to look for scapegoats. In the past it was schizophrenia victims themselves who were thought to be to blame. Their behaviour, which we generally describe as 'madness', was said to be due to indiscretions and indulgences in the past; to weakness of character; to evil spirits for which they had to be punished.

Then in the 1960s, when libertarianism was at the height of fashion, it was the family, particularly the

one who does not realise he is ill, they are criticised for taking away that person's liberty and the right to decide whether or not they want treatment. But if they don't treat him, they are accused of indifference and neglect.

With this background, it is not surprising that the policy of community care has been seen to fail so many people – each with an individual story of desperation and, in many cases, tragedy. I am told that nobody knows how many people suffer from schizophrenia in the community, how they are living, whether they are receiving treatment. That is one of the gaps that SANE will be aiming to fill urgently.

Then there is a need to encourage research into mental illness to improve understanding of the causes of schizophrenia and perhaps, eventually, to find a cure. Putting aside humanitarian and ethical con-



Princes Turki and Khalid with Marjorie Wallace. Their uncle, King Fahd, Keeper of the Two Holy Mosques of the Kingdom of Saudi Arabia is donating £1.75 million. The Xylos family, the Greek shipowners, have donated a further \$1 million

mothers, who got the blame. They were alleged to be giving their children contradictory messages and values to which the only rational response was to become disturbed. There has never been any evidence that parents cause schizophrenia in their children, yet the idea lingers on, heaping guilt on parents already hard-pressed and exhausted.

Today, it tends to be society itself at which the accusing finger points. Some ideologists maintain that schizophrenia is the result of poverty, unemployment and poor housing. I am sure these factors can't help, but there is not a shred of evidence that they cause schizophrenia.

No wonder then the public is confused by so many contradictory theories and consequently often rejects the sufferer in the midst.

Doctors, psychiatrists and other professionals work under enormous pressure. Like the families, they cannot win. If they intervene and give treatment to some-

considerations for a moment, when mental illness fills four out of ten beds (more than any other single illness) it is surely just sensible economics to invest a reasonable sum of money in the hope of discovering improved methods of prevention, treatment and cure. And the cost of beds is only one of the costs of mental illness. Research into disorders of the brain has recently become a priority in the United States and the 1990's have been designated 'The Decade of the Brain'. Leading scientists and doctors are confident the stage is now set for a great leap of imagination which could, within a few years, reveal the origin of this cruel affliction. Britain has some of the most able medical researchers and could make a major contribution to the breakthrough but (and I hardly dare say this when I know how many other worthy causes there are...) this will happen only if funds are available. ●

Patron:
HRH The Prince of Wales,
KG, KT, GCB

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In the community

SANE was founded in 1986 as 'Schizophrenia - A National Emergency' but has widened its concern to all serious mental illness.

It has three main aims:

- Awareness – to campaign for greater awareness and understanding of serious mental illness;
- Care – to pioneer care projects, such as SANELINE, and other ways of helping sufferers and carers;
- Research – to initiate medical research into the causes, treatment and eventual cure of serious mental illness.

BT is supporting, through its Community Programme, SANE's commitment to help all people affected by mental illness.

