In 1986, award winning investigative journalist Marjorie Wallace wrote a series of articles, "The Forgotten Illness", which brought into sharp focus the terrible plight of people with schizophrenia in Britain. This campaign led to the formation of SANE (Schizophrenic: A National Emergency) in 1986, a charity whose aims are to change attitudes toward mental illness, provide care and initiate research. Since becoming SANE's Chief Executive in 1989, she has recruited a network of key international figures from the fields of medicine, science, business and industry to support the SANE cause. In 1991 Marjorie Wallace set up an appeal to raise £6 million for research. SANE succeeded in obtaining that amount and is now in the process of establishing The Prince of Wales International Centre in Oxford for research into schizophrenia and depression. In 1992 she launched SANELINE, the first national telephone helpline for people with mental illness. Her previous experience in television has been put to good use for the cause and her latest documentary, "Circles of Madness", has been highly acclaimed.

Marjorie Wallace, MBE

You were a journalist before becoming involved in mental illness?

I studied philosophy and psychology at University College, London, and in fact did a research thesis on the effect of red and green lights on patients with schizophrenia. But my real interest then was the media. I worked in the early days with David Frost and in between series produced religious programmes. In this way I met most of the figures prominent in the 'swinging London' of the 1960s. It was a bubbly time. Peter Cook and Ned Sherrin and Bernard Levin would come on the programme to talk about their sins. Bishops and philosophers quarrelled like schoolgirls. I met scientists, politicians, poets, film stars, crooks and moguls – anyone who had become famous – from Harold Wilson to Dr Savundra. I then joined the BBC as a reporter and film director, appearing some days a week as an "intellectual dolly bird" in the early days of Nationwide. I loved doing these zany films, like pigs who sang opera, or the stress of looking after holes in the road in Blackburn. I also made more serious films, such as the first ever film showing the IRA being trained by the mercenary "mad Mike" Hoare. I remember that I and a small crew were taken blindfold at midnight from Londonderry, guns at our heads. The film was banned, but others showing the shipment of guns from Holland involving senior politicians were transmitted. I also made a documentary campaigning for people with mental handicap and mental illness to get out of mental hospitals. Ludovic Kennedy introduced the film, which was so distressing that he had to warn people of 'nervous disposition' to leave the room. I had never realised that the media could be considered so powerful.

While I was on maternity leave with my first son, Sacha, I met Harold Evans, then editor of the Sunday Times, on a tennis court. (I can't play tennis but like the company.) He persuaded me to join the Insight team on the Sunday Times, to interview thalidomide victims and their families. I helped write the book about the scandal and co-wrote a further book and a screenplay, "On Giant's Shoulders", which won the international Emmy award, among others, and is still being shown around the world. Following the thalidomide campaign, I became involved in a series of
Interview with Marjorie Wallace, MBE

other social and medical stories: growing old disgracefully, blind, deaf children affected by rubella, autistic children, the scandal of concrete systems buildings in the 1960s, and so on.

I got named as the "misery correspondent" by my colleagues, who always put the tragic stories my way. A two week contract turned into 17 years. In 1972 I won my first "Campaigning Journalist of the Year" award, and I was proud of the citation; it said it had been awarded for my "gift in combining great compassion with objectivity, urging the Health Service to take action about the treatment of disadvantaged people". I always hope that my writing still contains that mixture of rigorous research and conveys the suffering of so many thousands for whom life has become intolerable. I wanted to turn these moving and dramatic descriptions of people's plight into campaigns, so that something might change.

How did you come to be interested in mental illness?

My first introduction to mental illness came in 1976 when I met the mother of a girl suffering from schizophrenia, who was always in and out of hospital. Mother and daughter were locked in a desperate situation, each holding the other hostage; the mother not daring to leave the house in case her daughter took an overdose, yet being frightened to stay in in case her daughter attacked or abused her when overwhelmed by the voices. I could scarcely believe the horrific life they both led, in a nice suburban house, an otherwise intelligent mother, and talented daughter. The sorrow and grief experienced by this family and others whom I met at the time haunted me. But things were not nearly as bad then, in the 1970s, as they are now, because there was still the backstop of care in hospital, and if patients went missing, people at least tried to find them.

By this time I had married Count Andrzej Skarbek, a consultant psychiatrist, who was training to be a psychoanalyst. He took over the directorship of R. D. Laing's former clinic, the Langham Clinic, and it was set up in a different form, in the basement of our home. So although I did not write about mental illness then, I was exposed to the problems and the debates. I had started by being a great fan of R. D. Laing, like so many other students at the time but now I feel I did more damage than any person to the cause of mental illness. His brilliant writing masked unproven theories which, even if they were true, could only compound the pain of having a schizophrenic son or daughter, blaming the parents for their torments.

After the birth of my second son, Stefan, I had first hand experience of severe depression and it was three months before I could leave the hospital where he was born. However, I had to continue to work. In 1976 a factory belonging to Hoffmann-La Roche in Seveso, north of Milan, exploded, spreading the surrounding countryside with dioxins. I had worked on other environmental campaigns and this one interested me because of all the false reports and attempts to cover up the true scale of the damage. I visited there a few weeks after the disaster; my only advice had been to take an umbrella to prevent the dioxin-coated autumn leaves falling on my head and to "avoid walking on the contaminated earth". I returned there shortly afterwards and co-wrote a book about the incident, "The Superpoison", with Dr Tom Margerison. I continued to cover the story for the Sunday Times and in January 1978 I returned again, five months pregnant, to interview the women who had had miscarriages, a reported effect of dioxin. There, in a squalid hotel I started to miscarry myself, and a month later lost the baby. My life and my work had become a little too close.

Why did you go on doing this kind of investigation?

I think I was very driven then, to find out the truth about situations which could have been avoided and human tragedies which need never have happened. By this time I was working as the paper's social services correspondent. Some of the articles I wrote were photographed by Lord Snowdon. We worked together as an investigative "team" touring the country, and promoting campaigns for the disabled, deaf and other disadvantaged people. One of these stories was when I met Christopher Nolan, the severely disabled Irish poet, who later won the Whitbread prize. He could only use a pointer while his mother held his head in her hands, but in this way he wrote a poem for me.

"Amen and obsequies
a year's dream accrued
a baby."

Maybe he was prophetic, maybe it was chance, but my third son born two months later had hearing and speech difficulties, and for the first five years of his life had to undergo operations and weekly therapy.

What revived your interest in mental health?

In 1983 I received a telephone call from Terry Hammond, who was then working with a housing association in Southampton. He begged me to see what was happening in the move to community care. The more I investigated, the more I realised the policy was not based on research on how to provide better care and treatment for people with serious mental illness, but was a cynical cost-cutting exercise using apparently liberal ideology.
as an excuse for bulldozing hospitals and discharging thousands of patients into sordid beds and breakfasts, lonely bedsits or home to families who would break under the strain. I thought I was witnessing the casualties of a secret war.

Down in Southampton, supposedly one of the better places where the experiment was being conducted, I found people lost in Dickensian hotels and lodgings. I have never forgotten going to Dave's Guest House, when he collected his "residents" around, most of them suffering from mental illness. It was like a grotesque music hall scene, as they all joined in the chorus of how happy they were, while upstairs lonely, dirty figures were lying on urine-soaked mattresses. There were no washing facilities, no nurses, only people talking to their voices and swapping syringes and medications. At another place, an alcoholic landlady kept 11 Rottweilers to set on residents who failed to pay their social security giros. Down through underground labyrinthine passages that a man who believed the war was still on. Every day he would take out a wet uniform from the drawer and stand there in the windowless room, not daring to put on the light, because he believed the bulbs had laser beams which would kill him. Every day he would go back to the hospital from which he had been decanted, just to sit in the grounds. He had been told by the social worker who drove him to this hotel that it was "better for him". So had Nick, who was in the process of taking an overdose when we knocked on his room in a bed and breakfast. The landlady said she was afraid of what he would do, but could get no help from the social services, and when we took him to the hospital he was turned away.

Two weeks after my visit to Southampton, two of the people whom I'd interviewed committed suicide in their lodgings, and another was in Holloway Prison for attacking a passer-by. There was clearly a scandal, but research was scanty. It became more and more obvious that we had adopted, wholesale, a policy which had not been tested or costed. I felt outraged that so much hypocrisy should surround the decanting of patients into the community; there was so much jargon, so many buzz words, and even barely hidden blackmail from the ideologists, particularly social workers, who would castigate anyone who told the truth about how families were suffering. Anyone who criticised the policy was labelled as being 'reactionary'. And then there was the propaganda, which still exists, that all hospitals for psychiatric patients, whether they were built in the 1980s or in the 1930s and '40s were dank, outdated, Victorian bins, where people were placed "out of sight and out of mind". While being married to a psychiatrist and visiting many of these hospitals, I found these repeated quotes from the Government a ludicrous over-simplification. Of course, in the past hospitals had been used for the wrong purposes, were overcrowded and patients had been abused. But by the 1980s most of those who could live in the community had been rehabilitated. There had been many reforms and much upgrading of the old wards. Instead of bulldozing on these reforms and turning the asylums back into havens, and bringing the community into the hospital by using the grounds and facilities, all these resources were being squandered, sold off, with the money seeping back into the health authorities, without benefiting the mentally ill. The sufferers were indeed 'out of sight, out of mind' - in the community - and out of resources.

I wrote memos about the situation, but the then editor of the Sunday Times had other priorities and a downbeat subject like mental health did not feature.

In the meantime I had met June and Jennifer Gibbons, identical twins who had never spoken to each other. Bruce Matthews. He had been told that I was pregnant with my fourth child. As seemed to become the pattern, the birth of a play or book coincided with the birth of a child. I will never forget when my BBC producer came to my house to collect the final draft of the play. She could see that I was in labour but knew that if we didn't finish the last words of the dialogue, it would never be done. We did, and the ambulance arrived just in time.

Following the birth of Sophia, my daughter, I was ill again with attacks of viral pneumonia. While still recovering, I received a call from the then Managing Director of News International, Bruce Matthews. He had been told that I was keen to campaign about the neglect of mental illness, especially schizophrenia and the policy of community care. He gave me six months to work alone, as I wished, travelling through the country, to establish whether my initial reactions were justified. It was a very lonely time, because I had no-one to report to, no editor, no photographer or companion. I simply pitched up at various towns,
cities, villages; sometimes visiting the hospitals early in the morning, unannounced, or going to drop-in centres and meeting groups of relatives. I would spend nights on the street talking to the homeless, so many of them discharged from hospital then, who would stop taking their medication and were becoming very ill.

It was these articles, eventually run by the Times, under the editorship of Charles Wilson, which led to the campaign I thought would never happen. The response to the Times articles was phenomenal. I was told they had more letters on this subject than on any similar home news feature. Thousands of families and sufferers wrote to me, each story more harrowing than the last. In addition, opinion makers who had previously kept quiet on the subject began to speak out; some psychiatrists, magistrates, the police and voluntary workers dealing with the “hard end” of mental illness.

The Times wrote a full leader on the subject, money was sent in and I was allowed, by News International, to devote half my time to setting up a new charity, involving the great and the good, and of course the wealthy, to raise funds for research into schizophrenia and make grants for the immediate care of the sufferers and their families.

Why did you not join with one of the existing charities?

Existing mental health charities either held a very different viewpoint or were not in a position to join forces. MIND, for example, the leading charity at the time, was politically motivated by anti-psychiatry views, and its civil liberties background which did not take into account the liberties of the families. It was MIND’s policy which had been the inspiration behind community care in Britain, urging the Government to destroy every psychiatric hospital before community care could work. The National Schizophrenia Fellowship was not in those days the powerful organisation it now is. There was no full-time director, few central resources and they felt unable to help us with the demands of the response.

SANE came into existence about six months after the articles appeared, announced in a Times leader, “A Civilised Duty”. Our aims were to continue to increase awareness about mental illness, in particular schizophrenia; to educate the public and politicians, and lobby for more humane services. Our second aim was to fund research into the causes of serious mental illness (in the first three years we gave just under £500 000 to researchers in the field). Our third aim was to give immediate help to sufferers and carers, mainly via other organisations. For example, we organised a “Walk The World” with the NSF which raised for both of us over £100 000; we funded the sufferers’ group “Voices” for the first three years of its existence and gave substantial sums to Start Enterprise, an organisation working to rehabilitate sufferers in employment.

In 1988 the BBC asked if I would do a byline film to be shown in the Panorama slot. This film, “Whose Mind Is It?”, challenged the perceived wisdom on civil liberties and fought the case of those relatives who were taking the full burden of community care, and were given no rights at all. I made the film because I could not endure one more of these families coming to me with files of letters about the way they had been brushed aside, bullied into silence and told ridiculous things like, if they were to give food to their homeless daughter suffering from schizophrenia, they would be “colluding” with the illness and therefore the social services would take no further responsibility. The whole thrust of the mental health services was to exclude the families, but I could not bear the pain in their faces; tense, drawn and frightened. It was not just the patient but the family that was serving a life sentence through these devastating illnesses.

The film was followed by a studio discussion, where people who disagreed with this philosophy – particularly representatives from MIND and survivors groups – tore at each story, even laughing in the face of a mother whose mentally ill son had committed suicide. The programme stimulated several thousand calls and hundreds of letters. Many of them were from carers and sufferers seeking help and not knowing where to find it.

It was the experience of these calls that led to the idea of a helpline, where anyone could ring to get information about any mental illness and receive emotional support by trained volunteers. But that would demand huge amounts of money, and we were only raising about £300 000 a year, mainly through glittering events with our Patron, the Prince of Wales. We had garden parties and diamond balls (one of which was attended by the Prince and Princess of Wales), polo matches and celebrity golf. It was a deliberate policy to attract the attention of the successful entrepreneurs, chairmen of major companies, showbusiness stars and social luminaries. Schizophrenia was perceived as such a dowdy, unappealing illness, our aim was to try to rebuild its profile by association with the famous and glamorous. In addition, many of these people were rich and we hoped they would help with our fundraising.

I was still working at the Sunday Times, when in 1989 I was offered the Guardian Research Fellowship at Nuffield College, Oxford. I was given 18 months there to research campaigning journalism and to produce a lecture and pamphlet.
“Campaign and Be Damned”. At the same time SANE's Board of Directors, including the Chairman Lord Mottistone, then Lord Lieutenant of the Isle of Wight, Sir Campbell Adamson, then Chairman of Abbey National, former Director General of the CBI, and Lady Waddington, wife of the then Home Secretary, asked if I would be prepared to take over SANE as its Chief Executive. Would I be prepared to give up journalism? They encouraged me to keep on with my Nuffield fellowship, and for these 18 months I was resigned to a life of commuting, often changing in a lay-by to arrive at High Table in the nick of time. It was difficult doing both jobs and it was only in 1991 that I was free to devote myself full-time to SANE.

How did you cope with the move from being a journalist to coming to SANE?

The first funny thing was that being a journalist, I did not know how to read a balance sheet. Had I done so, I might never have gone ahead. But I gradually learned to read the accounts and now I'm pretty good at them. In the early days there were only three members of staff and a volunteer. Our profile was quite high - some important organisations such as the BBC and News International, even surviving the brutal move to Wapping, I had always believed there was a Big Daddy there to provide any money or pick up the pieces. Suddenly, as Chief Executive, I was on my own and there was no-one to step in and no funds to bridge a crisis.

What kept you going?

I would often long to go back to journalism, to my former colleagues, with whom I felt so much more at ease than in this strange new charity world. Sometimes I would sit there at 8 or 9 o'clock at night just staring out of the window, wondering how I could raise enough money to pay the salaries of our tiny staff. But then I would get a call from a patient or relative, and was spurred into action again.

So it was the families who kept you going?

Yes, and it is still the main motivation. Of course things are very different now: we have a staff of 29 and 120 trained volunteers. Our premises have trebled in size, our income quadrupled and we have reserves of over £6 million dedicated to our research centre, POWIC, and to shoring up our helpline, SANELINE. We still have to raise at least £1.3 million a year, which does not sound an awful lot in comparison with other charities, but it is exhausting work.

What are your particular skills in raising money?

Persistence and begging, and trying not to make people feel too guilty. I also try and do it with a certain amount of humour. Half my life is still going to these glittering events and I don't like the feeling that people will find me boring if I keep asking for money. I try to interest them in the stories and get them to understand a little of the suffering that I have witnessed. I know this is a very idealistic way of giving. I do not particularly relish a windfall such as lottery money, so much as really going in and fighting my pitch, competing and saying: "Look, what we're doing is really important", and making people believe in our work.

I was particularly anxious to find new money for our research centre, so that we would avoid taking monies away from existing sources. I was delighted to meet, through the painter Nicholas Egon, His Highness Prince Turki al Faisal, nephew of King Fahd of Saudi Arabia. He had no declared interest in mental health but responded to the argument that challenging the frontiers of the brain and how it works was a contribution befitting of his culture, his traditions. But it was not as simple as this. I did manage through Sir John Riddell, then Private
Secretary to the Prince of Wales, now a member of our Board, to arrange an informal meeting with Prince Charles and Prince Turki, at which everything was discussed except money. For months nothing happened, until a psychiatrist from Saudi Arabia turned up on our doorstep, saying that he had one week to see and evaluate the British effort in research into schizophrenia and why SANE should wish to create a new centre. That was a hard task, demanding quick arrangements, to which our advisors manfully responded. Then came the Gulf War, and I thought contact could be lost forever. So I sent a series of faxes to Prince Turki apologising for contacting him at such a difficult time (he was the Minister of Internal Security), but I hoped he had not forgotten SANE. I would get responses, telephone numbers to ring at certain times in different places, but there was never any answer to the hope that he would give a substantial sum. Eventually, three months after the war had ended, and following my last frustrated fax, I had a phone call, asking if I would lunch with him at the Dorchester. There, seated beside him and his businessmen (they called me an honorary man for the purposes), he announced that he would be able to pledge £1.75 million on condition that we matched this pound for pound from other sources. He also asked that instead of being called the King Faisal Centre, it should be called after our Patron, the Prince of Wales Centre. I was so excited, I rushed up to a phone, managed to contact the Prince of Wales immediately and got his permission to go down and tell them we were happy to accept this pledge. But raising matching funds proved harder than expected. Eventually Matti Egon, through her family, the Xylas shipping family, would contribute a further £1.75 million. At the same time I had been making many efforts to contact the Sultan of Brunei and was fortunate that Prince Charles agreed to invite him to play polo in a match to benefit SANE. In addition, through talking to the Sultan's emissary in this country, we were able to put forward a proposal and one day I went into the office to find that £1 million had been placed in our account. We raised over £400,000 through a Valerie Grove interview in The Times, and there were other donations. Fortunately we were able to put together a package of £6 million for a centre which will act as a forum and catalyst in the area of severe mental illness, in finding out the cause or causes of schizophrenia and manic depression.

Oxford University bid to host this centre, along with nine other universities, and was successful in that our advisors felt the strength of its neurosciences department gave it an edge over equally tempting bids. The idea was to harness powerful new technologies used in basic neuroscience to researching the cause of specific mental illnesses. There will also be collaborative research and a truly international flavour; SANE is working with researchers in other countries, as well as other universities in the UK. We have the plans, the site and Dr Tim Crow has already been working a year in Oxford with a staff of 17 researchers. It is an ambitious project but we have every hope it will succeed.

What about the helpline?

SANE's other major project, SANELINE, is expanding rapidly. We receive almost 1000 calls a week and can answer only a third of these. However, we have opened our first satellite helpline in Macclesfield, so that using an 0345 local charge number the Macclesfield volunteers are beginning to meet the huge demand and to take the overflow from London. Our next satellite will be placed in Bristol, and from then on we hope to move to Glasgow and to cover the eight health regions. Unique to the vision of the helpline is the blend of emotional support, with hard practical information not only about illnesses, symptoms, treatments, drugs and their side-effects, and mental health law, but in networking people into local services from sufferer support groups to emergency teams. In one call the volunteer can tell the caller all the services that exist in the Orkneys, in Aberdeen, in Belfast, Plymouth and all the London boroughs, so that if a son goes missing in Scotland and the mother, for example, lives in Manchester, during the course of one call we can give the telephone numbers, addresses and advice on how to access the help they may need in any part of the country. This database of services, now carrying almost 13,000 entries, kept up to date by a team of information technology experts, is the foundation of the helpline and makes it different from those lines where listening is the prime object, rather than using information as both therapy and an encouragement to action.

We are also continuing our arts grants and our awareness programme. We are continually lobbying ministers and officials in the Government, commenting on radio and television and writing articles for campaigns. In one year alone my PR consultant counted over 300 radio and TV broadcasts or contributions to major features. On one day last month I was rushing from ITN to the Jimmy Young Show to London Tonight, giving 15 interviews in the course of a day in response to the Secretary of State's announcement about new provisions for mentally ill people.

Could you say something about the more personal cost of running SANE and your work?

That is a very difficult question. I think it has taken a tremendous toll on my physical health. I do not believe that stress causes cancer, but I can
almost time to the day when I became ill – the day when I knew I would have to fight a hard battle against a competitive research appeal.

I also find the constant pressure of trying to fulfil the needs of the media very draining. At the end of an interview, when I’ve talked to a blank camera or had to produce a 30-second soundbite I feel as though my soul has been taken from me, utterly exhausted. People find it hard to believe, but the more you do interviews, the more you realise just how much rests on the words you use and the tone with which you convey your message. Because the stakes are so high, it never becomes any easier. I also find the responsibility of running an organisation pretty relentless, especially as without raising funds we could so easily become static and our visions blighted. Many evenings I go to social occasions where I feel I have to be bright and funny, so that people respond when I talk about SANE, but then I come home depleted, unable to give enough to my 12-year-old daughter, and that makes me feel so guilty. I think my family have missed out by my very long hours of work and the fact that weekends and evenings are still spent either raising funds or talking to sufferers and families or the media. I was delighted last year to receive the Evian Health Award for Best Use of the Media, but the work behind it has been gruelling.

**Why have you done it?**

There is so much to do to develop the helpline, to raise the profile of mental illness, that I feel to stop now would be to betray all those people, particularly the families who inspired me in the first place and who have given me such encouragement through the years. And I don’t want to face another horrific situation and say, "Sorry, I can’t help you", like everybody else has said in the past. People tell me that I must feel good about having helped establish SANE, but actually I don’t feel particularly good about it. I just feel frustrated that I have not been able to do more, and that things have not improved as much as they should. The beds are still closing, and the hypocrisy goes on. My dream is to liberate people from the torments of an illness like schizophrenia, and if they cannot get better, to make sure they are cared for properly and given the hope of the best medications and therapies we can devise.

**Is there any way you would like psychiatrists to help in your work with SANE?**

Yes. First I feel they should listen more to the families, even if a sufferer does not turn up for an appointment. If the relatives are there, they need treatment and care just as much, if not more. The other way psychiatrists can help is to increase the flexibility of second opinions. At SANEline we have a list of psychiatrists prepared to give second opinions and we would be grateful to increase that list. People may get stuck with one person and are too terrified to leave. Currently we have 120 lawyers round the country who give half an hour of their time free to SANEline callers. We would like to feel we had a similar network of psychiatrists. I also think they could be much more forthright in their campaign against the anti-psychiatry, anti-medication movement and those pressure groups who put ideology before humane care. I feel I’ve put my head above the parapet so much and am the target for many people who disagree with the mainstream medical approach. Privately psychiatrists say how much they appreciate my fighting, but many of them will not stand up and be counted. So many psychiatrists seem to have lost morale and are giving up. They are retiring early or following new careers. Yet from our analysis from the helpline, what the sufferers need most is a feeling that they have got a one-to-one relationship with their doctor, not just a key worker who may be untrained in mental illness. We would like to work more with the Royal College of Psychiatrists, and continue to work wherever possible with other pressure groups.

**How has your illness affected your life?**

Having cancer has made it just a bit harder, but it has also given me quite a lot of insight into being a patient and having to face chemotherapy. I was extremely glad the decision to continue was taken out of my hands and I was kicked through it by a team at the Royal Marsden Hospital. Their more robust intervention has at least given me two years longer to continue the fight.