

“Don’t talk rubbish, these tablets won’t hurt you”

by Stephen Corran

Sir Keith Joseph (1971) said: *“The treatment of psychosis, neurosis and schizophrenia has been entirely changed by the drug revolution. People go into hospital with mental disorders and get cured.”*

This quote is a suitable launch pad for my overall view of medication, which is intended to investigate the validity of treating emotional or psychological crises with psychotropic chemicals. This paper will, of necessity, look at the labelling process, which, in my view, essentially possesses a moral rather than medical judgement.

The chemical means to control distress is the first approach to treatment that anyone coming into contact with the psychiatric services will be offered. The wisdom, or not, of electing to become ‘a patient’, and everything the ‘sick’ role implies, is the subject of discussion in the following pages.

We shall look at whether chemotherapy actually works, perhaps considering the following comment: ‘The drugs work, not by correcting some bio-chemical imbalance, but by sedating someone to the point where they are indifferent to their relatives’ hostility.

The purpose of this piece, however, is not specifically to offer a criticism of the system that interprets internal disturbance or social deviation as an illness. I must, though, establish at the outset that personally I hold the understanding of life crises as ‘patterns of disease’ to be completely mistaken. I don’t think so called ‘symptoms’ should be dismissed, but feel that they have a meaning to each individual, the understanding of which would lead (possibly) to eventual healing and personal growth. I strongly

believe, as did R.D. Laing, that breakdown is purposive, and that under the right conditions can be a positive experience. Perhaps it would be too controversial to suggest madness may be a form of internalised ‘journey to the gods’ – i.e. out of oneself. If this ‘trip’ were successfully guided, one should return to a greater level of personal integration. Radically, I could see the madman as a shaman. Clinically, this would manifest as ex-patients helping future patients to go mad!! Rather too unsettling for many, I feel?

As it is, the biological approach is seductive to both physician and patient, promising something positive from the world of science, and all its certainties; the patient not having to feel his/her life is governed by irrational and disordered impulse. We all know the scenario – ‘Oh, doctor, thank you so much. I can’t tell you how relieved I am to know I have an illness. I thought I was going mad!’

It is strange (even after Freud) though, that people fear, even deny, their irrationality, yet, for example, are fascinated by their dreams and avidly read newspaper horoscopes.

The biochemical approach also, of course, removes the blame from patients, as their symptoms are explained away as mere chemical imbalances. People do tend to demand comfortable, non-confrontational solutions.

Before we move on to the labelling process, one of the functions of which will be to determine somewhat arbitrarily the drugs that will be prescribed, I think it would be useful to draw attention to the work of Rosenhahn, an American psychologist who, in his paper ‘Being Sane in Insane Places’, describes how he and his

researchers were admitted to a number of psychiatric institutions. Briefly, at interviews, they claimed they heard innocuous words like ‘thud’ as voices. They were admitted and once on their wards, spoke and behaved absolutely normally. All their behaviour, though, was interpreted within the conceptual framework of psychiatry. For example, one researcher who was making notes was said to demonstrate ‘compulsive writing behaviour.’ All, needless to say, were given the diagnosis of schizophrenia. It is not without interest to note that their fellow patients spotted there was nothing wrong with them!

It is also interesting to note, diagnostically, that some 150 years ago we just had ‘lunacy’. Now, according to DSM IV, there are over 400 sub-classifications of mental disorders. We seem to have reached the point where every nuance in human behaviour can be pathologised!

Rosenhahn coined the term ‘pseudo patient’ after this study, which raises vital issues as to the subjectivity of the psychiatric interview and the social and political bias of psychiatry. Once you have a label, all your subsequent behaviour is interpreted accordingly. To give a psychiatric label is judgemental and stigmatising; it would only be of value if it aided in one’s Recovery. Although, it has to be noted that some people do find their identity this way.

One of Rosenhahn’s observations was of the overwhelming powerlessness one has in an institution. Erving Goffman’s book, ‘Asylums’, drew attention to this and led to the study of the so-called ‘institutional neuroses,’ heralding the gradual emptying of the large hospitals. The systematic loss of identity and heavy

tranquillisation renders people passive, hence easy to control. As we shall see, the chemically lobotomised person is best suited for a life where there is a complete absence of individuality. I use the term 'lobotomy' due to the effect of tranquillisers on the will and the emotions.

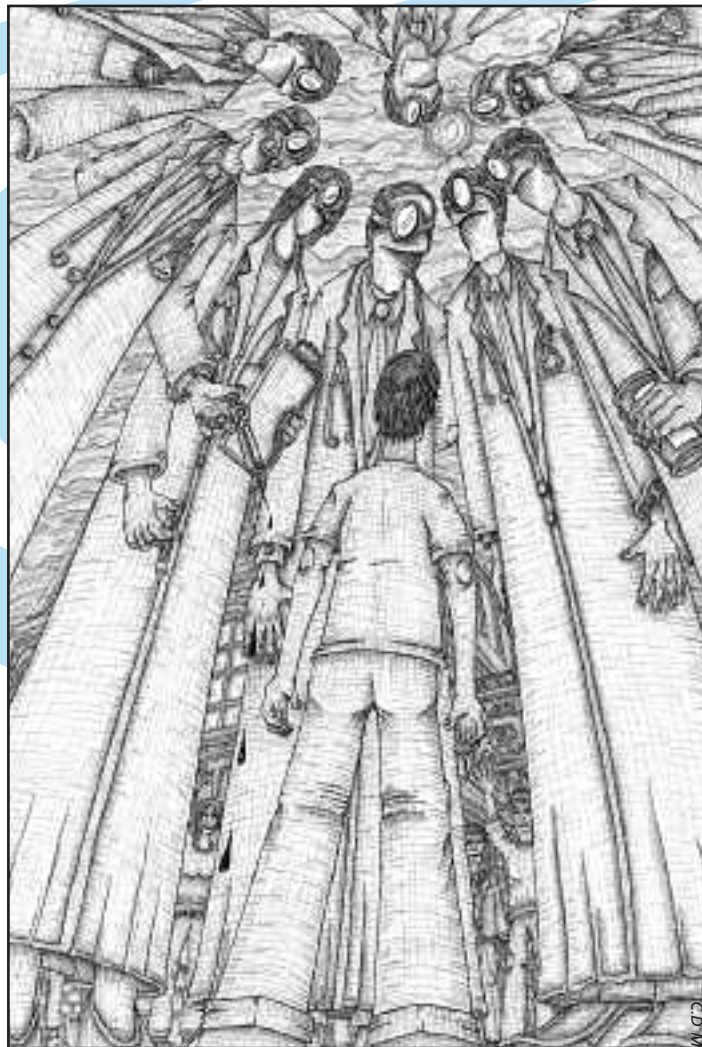
The above also applies, of course, to such establishments as prisons and care homes.

I have briefly touched on how labelling dehumanises and, personally, I tried to subvert this process by turning classification on its head. When I was in hospital we were all given hospital numbers. A friend and I derived great amusement by addressing each other using our numbers rather than our names. The hospital staff just couldn't understand this, which made it doubly amusing!

This loss of self is furthered by the insistence in the interview that you describe the most intimate, personal details of your life. Why? – I never discovered, as no one seemed to act on any information I might offer. This sort of exchange just reinforces one's subordinate role. I have often found that it is an enlightening exercise to turn the tables and ask the registrar if she has a satisfying sex life. The response is usually an education in itself!

It has always struck me that the interview is a very elaborate 'game'. However, there are counter-tactics that can be employed. For example, the following quoted by Laing: *"A young man is being asked if he hears voices – 'yes' he says. 'What do they say' 'they say – 'You're a bloody idiot.'"*

Possible misunderstandings arising from a poor interview can have frightening implications for one's future. I give such an example from my experience with a young, rather wet behind the ears, registrar. During the course of the interview, I had occasion to query something. She suggested a second opinion from the consultant. I had lost two consultants in my previous hospital through death by internal causes, and saw my chance here to test the skills of this person. I replied: 'I am not sure if that would be safe as I have the power to kill consultants!' I have never seen anyone write so much in such a short time! My white lie is preserved for posterity – she



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should have questioned me further on this point.

One final example of dehumanisation happened to me recently. I was at an out-patients clinic and told the consultant I was experiencing a certain level of anxiety when in crowded places or new situations. You should bear in mind that, due to my supposed schizophrenia, I have been socially isolated for over two decades. It is hardly surprising that, wishing to re-engage with my community and build a new life, my confidence was at very low ebb. Giving what was frankly an honest explanation of my discomfort, I thought I would appeal to his humanity. However, I was met with a cold stare, told I had 'social phobia' and that he could give me something for it. I felt so hurt, misunderstood, devalued and furious; I vowed to have nothing further to do with psychiatry. The system had robbed me of virtually all my adult life and where had I got? His negativity inspired great positivity in me, but I doubt he had the 'nous' to realise it.

I remember another occasion when my mental health workers once again made me feel bad

about myself. At one case conference they told me (quite incorrectly) 'You're an alcoholic, and a drug addict, among other things'. I was made to feel ashamed and bad about myself (in front of about 15 complete strangers), any guilt was reinforced.

I should now like to move onto the main topic of the paper. I shall deal with this by discussing three main points.

1. What drug treatments are available to deal with 'schizophrenia'.
2. How is each individual prescription, in terms of choice of drug and its dosage, assessed?
3. How responsibly is this treatment carried out?

I intend to illustrate the above by drawing on personal experience of anti-psychotic drugs, otherwise known as major tranquillisers or narcoleptics. These were largely of the neuroleptics group, the first of which, 'Largactil', appeared in the early 1950s; known to its detractors as the 'liquid cosh'. I was prescribed these for a period of over 30 years.

Psychiatric drugs are often given

in combination (known as polypharmacy), in spite of a 1993 paper on high dose prescribing which found fault with the majority of doctors. Polypharmacy is a clumsy and potentially lethal form of treatment which is contrary to official guidelines. I shall draw on an analogy that you should understand. Imagine being given a shot of whisky and not being seen to be feeling any effect. You are then given further shots of gin, rum and vodka. In short, you have a cocktail, all ingredients being essentially of the same type? Bear in mind, "A drug is a toxin with some beneficial side-effects." My personal cocktail, as I remember it, consisted at various times of the following:

- Stelazine
- Largactil
- Melleril
- Haloperidol
- Orap
- Depixol
- Modecate
- Imipramine
- Cipramil
- Epanutin
- Tegretol
- Epilim
- Hemineverin
- Diazepam
- Lorazepam
- Atarax
- Librium
- Buspirone
- Nitrazepam
- Flurazepam
- Temazepam
- Welldorm
- Noctec
- Zimovane
- Nembutal
- Disipal
- Kemadrin

Most recently, I was treated with the so-called 'atypical' or second-generation drug, 'olanzapine.' The effect was initially not as unpleasant as the first group, but it is by no means 'clean'.

The availability of these new 'atypicals' is largely a post code lottery as they are expensive. It is surely wrong that life altering changes to one's treatment regime should be made not by council decisions, but by economic ones.

In 1999, the annual cost of the average medical daily dose was estimated as follows:

- Largactil £23
- Depixol £300
- Clozapine £1800

However modern the pharmaceutical approach may be, in comparison to earlier physical

treatments such as hydrotherapy, insulin comas, ECT or psychosurgery, I maintain it is just as hit and miss. Each individual's response in terms of absorption rates in the gut and the blood/brain barrier is different. It must be stated that there can be no blanket rule in prescribing.

Malpractice in such an inexact science has been evident to me in many scenarios over recent decades. For example, on querying my dosage and asking if my blood/drug levels could be monitored, I was told this was impossible.

Side Effects

I should now like to consider the immense issue of side effects. These arise via the effects of the drugs on different systems on the body. I shall deal with them in no particular order. The major noticeable SE is tiredness, as this amusing anecdote demonstrates very well:

Synopsis: Epsom Derby Day Sandwiches/orange squash. Brown envelopes with lunchtime meds. Hour later L. Piggot is coming in on historic win with Shergar – whole world watching. 10 yards away from the finishing line, small circle of snoozing people on the grass!! Events of the world wide pass you by on Melleril!

Not only did I feel extremely tired, I virtually always experienced a dry mouth, and, paradoxically, excessive salivation to the point of drooling. The latter is socially embarrassing and the former causes you to take constant sips of water, necessitating frequent trips to the loo, but when you get there, sometimes nothing happens, as another side effects is difficultly in urination. I have known someone who had to be catheterised for this reason and steps had to be taken to deal with what came to be called his 'obsessive drinking behaviour.' I frequently became constipated; a friend of mine also, to the extent that he bled once and was subsequently examined for suspected haemorrhoids.

A massive side effect leading to inevitable embarrassment, hence not often aired to staff, is sexual dysfunction. This covers everything from varying degrees of loss of sexual interest, difficulty in getting or maintaining an erection, to complete loss of ejaculation. I remember mentioning this to my senior

registrar when starting a relationship with a young 'schizophrenic girl'. This lady doctor replied: "I wouldn't worry. It's probably for the best. You have 46% chance of having a schizophrenic baby." Our physical relations were at first literally 'sleeping together'! She certainly never needed a 'headache'!

It was, in fact, the same girl who asked her senior registrar why she had to have Depixol. This doctor replied "Don't worry 'why' dear. It's doing you a power of good. We give it for something with a long name most of us can't even spell". Apparently 60% of patients in the late 1970's were not told why they received anti-psychotics.

I will concede that I am writing of a time when you were placed in the 'sick role' and staff managed your life for you.

However, returning to side effects, I had a sensitivity to sunlight. The slightest exposure gave a sensation like insects crawling under the skin. Denial of this experience was apparent when I was given UVA/UVB treatment for eczema about 15 years ago, despite my protestations. It was agony. One may also be liable to be insensitive to extremes of temperature – possibly leading to stepping into a scalding bath (interpreted as self-harm!). I used to watch patients smoking cigarettes right down to their fingers without apparently noticing the burns.

I experienced weight gain and breast enlargement (especially on Olanzapine). This, (especially the first), is damaging to women's self image. I am not prepared to discuss the issue of breast size! I constantly had symptoms of pseudo parkinsonism, i.e. tremor with stiffening and weakening of the muscles. You can picture trying to lift a glass (too heavy), move it to your mouth (too rigid) and, if you're lucky enough to get it there, you've been trembling so much you've spilt half of it down your shirt! Again, extremely socially embarrassing. Common, also, are gyrating thumbs – known as pill-rolling.

I used to shuffle around and had a wooden mask like expression. It often isn't so much the psychiatric condition that marks you out, it's the visible effects of the drugs. I remember going into a shop a few years ago. The woman

served me and said to a friend of hers as I was leaving "there goes another one from the funny farm". Such comments are deeply hurtful, yet if one can summon the strength to realise it, you may be confident that such a level of mindless ignorance reveals that the main problem is not yours.

Woody Allen wrote:

"Cumulative side-effects took their toll on my perception, and when I could no longer tell the difference between my brother Morris and a soft boiled egg, I was discharged."

Another predominant side effect is a tremendous inner restlessness. One has to constantly move to dissipate what seems to be an ever increasing pressure inside one's limbs.

If you can imagine lying in bed, trying to sleep, but you can't because your legs have a life of their own – they thrash from side to side – it is actually painful to try to keep them still. Compulsive movement helps. I used to call the marching on the spot 'the phenothiazine shuffle'. I doubt, though, that it's a sequence you'll see on 'Strictly Come Dancing'! Incidentally, this restlessness may be wrongly interpreted as agitation or anxiety, leading to increased doses of the offending drug.

An extremely nasty effect is known as 'oculogyric crisis.' My eyes would roll upwards so my visual field became the ceiling. I had absolutely no control over this. What I dreaded most was the accompanying feeling of a terrifying foreboding which would sometimes last a few hours.

Incidentally, on three occasions I was prescribed combinations of drugs to treat both physical and psychiatric conditions with potentially lethal effects; Namely, I was once cheerfully told, 'sudden death syndrome'. It was this that killed Sean Walton at the Ashworth Hospital in 1990. High doses injected in combination can prove too much for the heart. The coroner's verdict is normally 'death by natural causes' – a whitewash. For many years my pulse ran at 110/120 beats per minute. No one raised an eyebrow, even when my body temperature was found to be up by about 1 degree.

I should also introduce the contentious issue of 'iatrogenic illness.' It is questionable whether a drug, that in treating condition

A causes a secondary condition B, should be used at all in clinical practice. For example, use of anti-psychotics can lead to jaundice and potentially fatal cardiac arrhythmias.

At various times I have had an inability to cough or swallow. The inevitable outcome of this is, of course, inhalation of and choking on food. Not being able to swallow would drive me up the wall at night. The only way to make the reflex work was with a mouthful of water and I had to try and sleep sitting up as it made the process easier. My respiratory system was also affected. I suffered from sleep apnoea, meaning a cessation of breathing at night. When something made me realise I was not breathing, there would suddenly be an enormous, noisy intake of air. This conjures up a picture of everyone's perfect pest in the dormitory at night. The silence of the early hours would be interrupted by the sound of thrashing legs, mattress squeaking with a jack-in-the-box who periodically gasped with the desperation of someone fighting for their last breath. Not a recipe for peace.

It was commonplace, before the emptying out of the big institutions, to see wards full of men and women grinding their teeth, grimacing horribly with tongues sticking out. It was often pointed out to me that I was doing all or any of the above, although I did not realise. My arms would sometimes jerk.

Although, on reflection, I seem to have painted an extreme picture, one should bear in mind that my body suffered a non-stop 26 year bombardment of extremely high doses of medication, often given in combination. Individuals' physiological responses differ widely too, as I have established. I think it is a marvel that this essay is not reaching you from the afterlife!

Now we come to what may be changes in gait and posture. I remember once, on an insanely high dose of Stelazine, finding walking almost impossible. As I went along, I began to lean backwards to the point of almost falling. This must have presented an amusing picture. Imagine a figure proceeding hesitantly down a bustling street leaning stiffly backwards at an angle of 30 degrees. It occurs to me now that John Cleese might have liked to

borrow this one!

Every ten yards or so, I had to stop, straighten up and lean forward almost to touch my toes. I knew I must be drawing some attention, which, of course, accentuated my feeling of oddness and of being under observation. When I reported this difficulty, admittedly the dose was lowered, but I know that these socially crippling effects were viewed as secondary to the supposed benefit to my mental state. Indeed, I would go so far as to venture that side effects were understood to be regrettable, although an inevitable part of one's life. One of two wiser nurses admitted to me privately that this was no cure; my symptoms were merely being masked.

Yet another side effect that I experienced was grimacing and twitching. These are both a sign of Tardive Dyskinesia; irreversible neurological damage.

I am told that this damage, often only really noticed when the drug is withdrawn, is best treated by resuming the drug! Tardive Dyskinesia is a proven fact, though most doctors in my day were in denial about it. Far from being the panacea one was led to believe, in 1992 it was estimated that some 500 million people world-wide had used major tranquillisers, of which 86 million had succumbed to Tardive Dyskinesia permanently. It has been said:

"If schizophrenia were less debilitating, narcoleptics would probably be withdrawn on grounds of toxicity."

Any benefits of a drug should be examined in the context of its use. This group of drugs might better be described as a chemical bull in a china shop – unpredictably interfering with a wide variety of bodily systems. The drug clozapine was referred to in an episode of the X-Files (when used with temazepam) as causing "widespread unpredictable behaviour".

It should be a serious concern that a drug cannot 'cure' mental disturbance - so we must ask whether achieving nothing of real value in the long-term, yet causing actual neurological damage, these drugs should be used at all? They are still over-used and their role is over-emphasised, as I found when I telephoned the ward in Epsom where I had received most of my

treatment. I spoke to a young staff nurse, who, when having explained myself, commented – "You sound very well". "Yes, I am extremely well". "You must have been taking your medication!" This came from someone 100 miles away who had never met me and, I suspect, wasn't even born when I spent time on the ward. I never cease to be astounded by such reliance on a form of treatment that patently only touches the surface of the problem.

I think now it is realised that social problems cannot be cured by a pill. However, I feel the judicious use of medication to calm someone and bring them to a rational appreciation of their problems, to a point where they can be 'reached' and empowered to access organisations that can help get their life back on track again, is valid. Really, as the reasons for breakdown are multifold, so are the ways back to wholeness. We are predominantly social beings with many different needs.

It has recently hit the headlines, I am glad to say, that we have an immense problem with the prescribing of anti-depressants to children. Not before time, it is being suggested that more 'talking therapies' should be introduced. I would extend this to alternative or complementary therapies, where the mind/body relationship is viewed more in terms of harmony and integration. We all have the potential to self-heal if we can learn to utilise the right methods. If a tablet can make us feel better, we, through changes in our lifestyle, can effect the changes in chemistry naturally. Often, the list of side effects is longer (and more discomforting) than the symptoms the drug was designed to control. As Eli Lilly famously said: *"A drug is not a drug if it does not have side-effects."*

I am sure we all shrink with horror at the thought of a 5 year old on Ritalin or Prozac. Consider this possible scenario. A troubled and hurting child has a one-off incident, which, if mismanaged, escalates to medication, appointments within social services, finally possibly being taken into care. I have known several people who have slipped into long-term psychiatric 'careers'.

How sad it is, also, to see elderly

people who were determined to stay independent, being admitted to hospital and being 'broken' by medication, as they were becoming a 'management' problem.

I am led to understand that there is no known deficiency of serotonin in depression. I never had my dopamine levels assessed. Incidentally, did you know that it is said an injection of blood serum from a 'florid' schizophrenic will precipitate a 'normal' person into a psychotic episode? Also, that if you give LSD to someone florid, it will have no effect whatsoever?

Returning briefly to Tardive Dyskinesia, in addition to the physical manifestation is a mental sluggishness called 'encaphalitis lethargica'. Personally, I noticed a monumental inability to think straight or to feel anything (also known as 'tardive dementia'). If I complained about side effects, I would get the following sort of responses:

"Don't talk rubbish. These tablets won't hurt you." "Your so-called side effects are attention seeking". "Oh it's all part of the illness." "Let me reassure you, there are no long-term effects from these tablets." (The best comment on high doses came from a fellow patient): "I wonder how much blood Stephen has in his Largactil stream!"

Many years ago, after a failed attempt to give up chemotherapy (which lasted 4 months), I was threatened with section 25 if I did it again. It seemed that the medical staff cared more about control than one's quality of life. I should mention, in passing, the abuse of psychiatric drugs in the punishment of political dissidents. It is an interesting paradox to find substances that were intended, and I would happily concede this, for the alleviation of suffering, being so commonly used to cause it. One has to conclude that in the hands of man, anything can be a two-edged sword. The ability to split the atom comes to mind.

On the subject of dosage, for a good 10 years I was prescribed a dose of Modecate, 4 times the maximum recommended by the BNF (this type of prescribing is known by the lovely expression 'megadosing'). In fact, I remember, one morning, there was slight argument with the practice nurse. She called in my GP who said (as if I wasn't there),

"he doesn't normally cause us any trouble, give him another 100 mgs". So I had 6 weeks dosage in 5 minutes, having had 4 weeks worth the week before and the prospect of the same in 7 days time.

It was, incidentally, the same GP who refuted all my insistent claims that I was over-prescribed. I might add that my CPN did likewise. He also kept me away from psychiatrists, who, as he put it, would 'tip the applectart'. If you are compliant and fairly quiet, nothing radical in your treatment will ever happen.

This does raise questions as to the value of so-called 'maintenance therapy.' I accept that relapse rates are lower when medication is continuous, but not significantly. Surely, it would be better to enjoy a quality of life and perhaps to risk an uncertain future. It is interesting to note that the overall outcome of 'schizophrenia' has not improved since 1954 (introduction of Largactil). One registrar revealingly said to me: "Stephen, you improve or worsen despite your medication!"

Over 10 years prior to 1989, I had had varying dosages of Depixol and Modecate. I daren't try to assess how much oral medication I have taken. To me, it is no wonder I have little sense of internal cohesion, and experience a loss of memory and a lack of ability to think straight. If I had claimed such mega-dosing was a conspiracy to keep me quiet, any outburst would have been regarded as a symptom of my paranoid state. It is, however, a truism that even paranoids have enemies! Psychiatry is full of such contradictions. I am reminded of the person who says he feels very well, who is then told that such a statement means that he is actually very ill. I don't deny this may be 'clinically' true, but we are caught in a linguistic web, and, like a politician, your psychiatrist will be good at manipulating words.

I will finish this section by noting that my newly-appointed support-worker was told not to be astonished at the grey/purple discoloration of my complexion, due merely to the extremely high doses I was being prescribed. I hadn't even noticed this in the mirror – presumably because my vision was so blurred!

To attempt to move beyond a

more medical approach, which is what most service users and survivors want, we need to view ourselves as complex beings who relate to the world around us in many ways; the relationship between mind and body is very subtle. I don't believe that we are closed systems in which things happen in a simple chain of cause and effect. Our environment reacts on us and changes us, as we affect our environment.

To treat disjunctions in such a relationship (i.e. life crisis) as diseases raises social and ethical questions. One might ask why, for example, depression/anxiety and ADHD are on the increase? We can look for answers in stress at home and in the work-place, dysfunctional families and relationships, poor diet, and lack of exercise for example.

New ways of working: A different mode

It is regularly requested that safe places to go through periods of distress are needed, places that do not intervene medically. Probably the high reliance on physical treatments reflects a lack of community support/counselling/housing/opportunities for work etc.

If medication has to be used, it must be done with informed consent. Often, when one is first admitted to hospital, it is in a state of extreme excitement and, although I have given the impression of being anti chemotherapy, I have often been glad to be slowed down, both physically and mentally, in order to get some rest. I do think there is an over-reliance on it though.

It is at the point when one is quiet enough to be receptive that different approaches should be suggested. At the time of my various hospitalisations, things were 'done' to and for me. The valuable contribution psychiatry could make would be to aid the distressed person to piece together his/her internal jigsaw and evolve to pursue their lives in as fulfilling a way as possible.

The patient's charter states:
"You have the right to have an explanation of any proposed treatment including any risks involved in that treatment and any alternatives, before you decide whether to agree to it. You can expect to be told what treatments are available other than medications."

Our distress must be taken seriously and we must be listened to. There is often much unresolved anger which needs to be channelled, not suppressed.

In conclusion, I feel the most important contributions psychiatry could make to improve everyone's lives would be to boost confidence and combat loneliness. It would be a move away from medicinal control to social care. I have often felt that the most crippling side effect of the estranging conditions called mental illness is the isolation and pain of loneliness. It is more responsible for the 'revolving door syndrome' than the 'illness' itself. Many times, on readmission, I have heard people say: "How nice to be back here with all of you to talk to", a very sad and telling comment on our so-called society.

We all need the respect and love of others, to be given hope and to find value and meaning in our lives, through a sense of belonging. We need essentially quality of life.

Fostering the above would, I feel, be TRUE SOCIAL INCLUSION.