Not quite what the patient ordered

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In the last of the group of papers from the conference on inatrogenic disease which we are publishing is this issue Katharine Whitehorn told the audience mainly of doctors and doctors in training – and tells many more through this Journal – what the patient expects from them. She envisages a generation of doctors who are coming to see their role rather differently from that of their fathers, and perhaps in the future a new medical scene.

The title of the conference is 'Not quite what the doctor ordered' and the title of my speech is supposed to be 'Not quite what the patient ordered', but I'm not quite sure that I am what *you* ordered. I tend to fill this role of Statutory Outsider to the medical profession, but it is slightly spoiled by the fact that I enjoy very good health myself – and I must say the more I have to do with doctors, the more determined I am to go on that way.

My own most recent experience of a medical side-effect goes like this. I ricked my back carrying a crate of whisky into the house, and my doctor gave me some pills for it. They made me very sick indeed, so I stopped taking the pills – but meanwhile my husband's neurologist had knocked him off the whisky, and the side effect of that medical decision was to let me off carrying the Scotch – as good a side-effect as I can think of.

I'm also untypical in that I am, I think, a Good Patient. I carry round my kidney transplant card – at least I did; when I found I'd written my telephone number on it and given it away, I wrote conscientiously in my diary on Boxing Day – insurance number, office number, next of kin, blood group and the phrase 'OK to take kidneys etc' – though I admit on the day after New Year's Eve I added 'liver not recommended.' And it's as a Good Patient that I have highly mixed feelings about this questioning and criticism of physical medicine that every intelligent doctor seems to be doing just now.

True, I live next door to a young man in his early twenties who has grown up blind as a result of too much oxygen given him as a premature baby. And for years I used to visit a nearly-blind old lady who had gone into hospital for something fairly trivial and come out with this much worsened eyesight. But on the other hand, my 72-year-old mother is at the moment getting over a dose of double bronchial

pneumonia from which, I imagine, she would once have had scant chance of recovery. And I think I wouldn't be alive today if no-one knew how to cut out an appendix. I know this one is high on Ivan Illich's list of unnecessary operations; but mine was a real emergency: I know this not so much because they kept ice bags on it all day as that they finally operated, in France, on a Sunday.

You need to keep both ends of this perspective in view – and nowhere more than when you are discussing the psychological aspects of treatment. What interests, I won't say alarms, me as a patient is the extent to which the sort of treatment you get seems to depend on whom you happen to see first. Mia Kellmer Pringle, of the National Children's Bureau, has a horror story about a friend of hers, a working mother and therefore suspect from the start, whose child suddenly in the middle of the night developed what were clearly psychotic symptoms. She rang Mia and poured it all out in a flood: her guilt, her self-accusation, the ways in which (undoubtedly) she had done wrong by her child . . . Fortunately this highly sensible lady cut her short by asking 'Have you actually taken the child to a doctor yet?' And it turned out that she hadn't; and when she did, the child was found to have a (admittedly rare) side effect of the travel sickness drug found in Kwells; three or four weeks careful nursing and she was all right again.

But supposing that woman had first gone to an over-committed psychiatrist? Would they ever have found out about the Kwells? Irving Cooper, too, has written a whole book about the fate of those with *dystoma musculorum deformans*: half of them got some relief from medical treatment, but the ones who fell into the hands of psychoanalysts first never got any.

Of course, these stories work both ways round. I'm not suggesting the cure is always to go and see the physical chap first. I worked for years with a man who had a bad back all his life: he was supposed years ago to have a slipped disc, and was sent to the slipped disc man, who slit him up the back like a kipper; on finding no slipped disc the surgeon stitched him up again and lost interest, but he's had the bad back to this day. His condition was really much more complicated than that, caused by being by temperament a homosexual farmer, yet having to work as a woman's page journalist. No way of undoing the effects of his operation now.

What is the patient asking of the doctor?

We come to you for advice: but what sort of advice do we really want? What is it the patient is after? It is too easy to assume we all want the same kind all the time. Why is it that if you are a fairly experienced mother of five, the fifth child doesn't get to the doctor nearly so often? I know there are people who would say, 'Well, of course, you are more secure in your mother-child relationship' – but it's equally true to say that by number 5 the chances are that some of the elder children have had most of the easy things already, and you have the medicine right there in the medicine cupboard waiting – so you can leave the doctor alone. Again, the first time your child rushes out of the school swimming bath, like Archimedes, crying 'Verruca! Verruca!' you go to your GP, who gives you something mild enough for you to dab on yourself, and it goes on for months. The second time you don't muck about, you go straight to a chiropodist who deals with nothing but feet; she straps on a bit of quicklime or something and the whole nonsense is over in a fortnight.

It's absurd to pretend we never want this kind of mechanical advice. Why are chemists distinctly easier to deal with than doctors? Because they don't bother with all the background chat; you just say, 'I'm feeling terrible *here*' and they give you something for it. I didn't, I'm ashamed to say, know until this conference that there was a move to extend the role of the friendly neighbourhood chemist, but I'm all for it – I would disagree with one speaker in just one thing, though: I think chemists *should* go on selling hot-water bottles and combs. For the same reason, exactly, as I think nurses should go on making beds: that it's so much easier to talk to anyone if there is some sort of physical transaction going on as well. You know how easy it is to chat to children over the washing up – though not easy to get them to wash up, of course. 'The problem of communication' is very often the dishwasher. And it's easier to talk to someone who is dusting round you or making your bed than to say, 'Nurse, I wish to communicate' – even if she hears you right.

Rather than have you decide what sort of advice we need all the time, I think we have a right to choose, ourselves, to go to different sorts of people for different sorts of advice. In a good group practice, this is already happening: if you've any sense you don't bother to get the doctor who knows you best if you just want the ear wax blown out or if the child has fallen off the table at school and needs stitches over his right eye, again. But if it is part of a long, continuing saga, then you do need the one who knows the story so far. So even within the medical framework, different kinds of advice are available on demand – on patient demand, which is what I think matters.

Why do women's lib suction abortions appeal so much to the American woman? They satisfy patient demand by bypassing that organ which I would consider to be even more inessential than the appendix, which is the male medical practitioner's conscience about organs which he himself does not have. As the woman said of the Pope and birth control: 'He no playa da game, he no maka da rules.'

Doctors' expectations

But it isn't just patient expectation that comes into it, alas – there's doctor expectation too. I was fascinated, in a ghastly sort of way, by your session this morning – especially by the man who kept on standing up and relating the phone calls that had woken him fruitlessly in the middle of the night. Because what was he actually saying? That these people shouldn't have *had* troubles? Or that they weren't his business? If you're feeling rotten at 3 in the morning because you can't sleep, you can ring the Samaritans if you feel like committing suicide; that's all right. Or you can ring your mother, which is OK except for the wretched mother. But if you ring your GP, he resents it because he expects you to call him only if there is something he can actually do before tomorrow morning, surgery time. But is that a realistic expectation? How do you know whether he can do anything or not? How do you know he can't give you the advice you want? You doctors have, in fact, got a wider advisory role for plenty of your patients plenty of the time; and I don't see how you can abandon it just because it's after hours.

Nor do I feel you should stop feeling responsible for doing something about our pain – of whatever sort. Ivan Illich is worried because we can't cope with our own – well, fine. But I can think of nothing more dangerous – and only brilliant ideas *are* dangerous – than encouraging all you strapping healthy young men and women in your twenties to take an even more casual view of other people's pain than you do already. It reminds me of that description of 24-year-olds at funerals: he said 'They shift embarrassingly from one foot to another – they, themselves, are never going to die, so the whole thing is boring and irrelevant.'

What you have to remember is that what gives you your power is fear – and that the fear existed long before you had much power to do anything about it. It's the story of the man talking about the Outer Hebrides to an old farmer there: 'But what did you do before you had the flying doctor?' 'Well, we mostly died.' Just so – but we don't want to die. 'Dogs!', said Frederick II to an army understandably reluctant to go into battle, 'Do you want to live forever?' Of course we do.

Learning to live with pain?

And why I'm so alarmed about any of these back-to-nature moves is that it is easy to abandon the pain-controlling systems we've got now, but very much harder to get back to the ones they had then. A striking case in point is natural childbirth. Vivian Merchant, wife of Harold Pinter, wanted to have a childbirth that should be as much like the natural performance of women in a primitive condition as possible. Only she had a deep transverse arrest, and they dealt with the whole thing without so much as a whiff of gin. At the end of it they said 'Well, Mrs Pinter, you've had your natural childbirth.' It took her nine years before she could even look at a pregnant woman on the street without horror; she's certainly never had another baby. Easy to remove pain killers: not easy to produce the primitive strengths that managed without. Sometimes I feel the back-to-nature lobby is giving advice that is as hard to follow as the advice I gave myself when under the influence of pentathol, having my own baby. There was an argument going on over my distended abdomen as to whether some £20000 they had should be used for research or for more beds: 'Ridiculous', I thought, 'they ought to use it for more time between contractions.'

And when people say we should all be more trained to cope with pain, they forget, I think, how it's done – and how much at variance that sort of fortitude is with most of the other things enlightened educationalists believe in. A PR man called Gaston de Chalus told me about his school-days once: he was beaten every Saturday if his Latin was bad, 'I never did learn any Latin', he said, 'But I have a wonderful resistance to pain.' There was a man, too, who commented on westerners in Vietnam: 'In the western world the middle class child is king; he is not used to pain and suffering'. The people who could cope with pain were often those who'd known little else: one would hardly wish the Vietnamese training on anyone. It's a great paradox that in the days when three-quarters of all children died people asked priests how to bring them up; now 99 per cent of them live, and we ask a doctor. But a quick look at what's happened in paediatrics hardly encourages one to rush into an abandonment of the entirely medical role.

Any treatment is good given with love

In the thirties, you had very strict hygienist regimes, you fed the child every four hours on the hour, and even if your frustrations were trickling down the front of your blouse you weren't allowed to pick up the baby till the clock struck feeding time. Obviously this was foolish and bad – but the people doing it did at least know what they were doing. Then old Spock came and said, 'Do what you like so long as you're enjoying it – and as in the normal way you

don't enjoy it; half the time, the mothers felt doubly guilty and awful. Nowadays it's even worse, because we can apparently do just about anything to our children so long as we *love* them enough – and really do not contemplate with any equanimity from the patient's point of view the situation where doctors are allowed to do absolutely anything they like so long as it's done with love.

It is also entirely proper that you, from your doctor's point of view, should constantly question what you are doing and should question your wholesale use of any of your methods, whether it is drugs or surgery or whatever, but from the patient's point of view, I feel very hesitant about the wholesale condemnation of drugs. Drugs is one of these subjects that seems to divide along the line of age. If you are over 30, you are pro aspirins, pro Tofranil, and above all pro alcohol. If you are under 30 (or wish to be thought so, which is an even more dangerous condition), you are pro cannabis and anti the drug companies. But from the patient's point of view, the great thing to be said for drugs is that they are a great deal more under your control: you can always stop taking them. The alternatives to drugs in practical terms are usually either surgery or psychology, and they seem to me to be very much more susceptible to high priestism and bullying by doctors. Indeed, I think we are becoming very well aware of the extreme dangers of surgery charging ahead without reference to social consequences. Spina bifida is the obvious case in point. If the surgeons had actually to look after those children at home for 15 years, I think we would not see very many more of those operations. And the reason heart transplants are considered discreditable, apart from all the emotional ones, is that this was pioneered in a country where the black population has one doctor per 50 000 patients. It is, if you like, an esoteric specialty that has gone beyond all reason from the point of view of the ordinary patient.

But I would say that there were perhaps equal dangers about the wholesale tendency to assume that you want a more psychological approach. Usually, when I am talking to doctors I am trying to tell them that the patient is a bit more than a colon attached, unfortunately, to a person. But with you, I don't now find that argument needs making, and it's highly encouraging that it doesn't. But perhaps one has to warn against the dangers of going too far in the other direction. You see, I would accept Illich's idea that salvation and health are very much the same thing, but I think there are great dangers in everybody deciding beforehand that what is wrong with me is something sociological or psychological: it leaves me with too little say in the matter.

I have got a friend who is married to a film star and he is often away on location for months at a time; so she has got lots of time and goes to Balint doctor. She does not get so much as a nos-

drop without 20 minutes' discussion. This is fine; this satisfies her need. It is just as wasteful as any other way, but that is what she wants. There are others of us whose attitude to our own complaints is much more like the attitude one has to something that has gone wrong with the car. It is a mechanical defect, it is a dead bore, and can you kindly give me something to cure this as quickly as possible? I am not saying that one attitude is not as unrealistic as the other: I am saying that we are both patients, and that we want different things.

When somebody says, 'Why are you putting yourself in the patient role?', well I am putting myself in the patient role this morning, doctor, because some clot put the lid back on the metal casserole so that it did not completely fit; and when I brought it down from the shelf the lid flew off and has knocked me across the forehead. Would you kindly stitch it up and I don't want psycho-analysis this morning.

Professor Marinker mentioned Dr Winnicott who is, after all, the high priest of psychology, but I was greatly cheered when I was interviewing him that he said what he would like to do if he was younger was to be able to be a complete paediatrician, which he said meant dividing it fifty-fifty on physical-psychological medicine. (His medical history by the way was absolutely fascinating. He was an expert on rheumatic fever in children, and then it went away, so he had to become a psychologist.) Somebody said: 'How irritating if your specialty disappears! You can't even sue it!'

There are people who want mystery, and people who don't; people who want one sort of advice and

people who want another. The other day I was talking with some Citizens Advice Bureau workers in training, and they had realized that what drew them to the work was the degree of involvement they could offer – enough to be in close touch, but not the all-out involvement of priest or social worker. And if there's a whole range of the sort of advice various helpers and workers feel capable of giving, I think there's a whole spectrum in the type of advice we want, from the crisp two minutes of the bank manager to the in-depth encounter with an analyst. Doctors, perhaps have to cover the lot: all the way from high priest to garage mechanic. And one day, perhaps, we'll be able to choose what we get.

The medical set up of the future

I see the medical set up of the future as one where the distinctions are far less hard and fast. There will be the hospital, the central shrine – probably disused for the most part and empty from lack of funds: the hospital will be the church of the future, and visitors will be shown where the heart used to be cut, much as they are in the Aztec temples of Mexico. From the central high priest (attended by his handmaidens Tibia and Fibula) there will be a whole range of lesser medical people, shading off into those who are not really doctors at all – but the slightly medical, the very medical and the so medical as to be totally sublime – will all in their different ways be doing the same job. I would put it simply like this: when we want extreme unction we'll ask for it, and I hope your profession will do the same.