

Pain Relief – a Human Right?

Scargill House

27th to 30th June 2005

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Introduction

The fifth of a series of annual meetings on philosophical aspects of pain medicine and the first of the Special Interest Group of the British Pain Society for Philosophy and Ethics.

On the Global Day against Pain, October 11th 2004, the IASP and EFIC together with the WHO declared that pain relief should be a universal human right. This is a noble intention and should prioritise the addressing of huge unfulfilled needs both in the developed and developing world. Nevertheless in a world of so many conflicting priorities (which in too many countries include the provision of the most basic of medical care) some doubt is bound to arise regarding the realism of such a proposal. The IASP and the WHO have made commendable efforts towards improving the treatment of cancer pain in developing countries, especially as regards availability of opioids, but there is much still to be done. Even in a rich country like ours we have all experienced frustration in trying to provide as good a service as we could have wished with a better share of resources.

The first day's proceedings, led by David Greaves, were devoted to exploration of the philosophical implications of the Declaration and some practical aspects of its implementation. Minha Rajput described her experiences of trying to improve management of pain in Kenya; Andrew Chmielewski reminded us of our wider responsibilities as pain professionals in the developing world; Ian Yellowlees brought us back to the realities of resource allocation in our own practices, and I presented post-amputation pain in landmine victims as an example of gross deprivation of human rights in this context.

The second morning's discussions addressed the ethics of the drug industry. John Le Carré's novel *The Constant Gardener*, recently released as a film, portrays some of the worst examples of corporate greed perpetrated by "big pharma" in the Third World. Le Carré has written "As my journey through the pharmaceutical jungle progressed, I came to realise that, by comparison with the reality, my story was as tame as a holiday postcard."¹ While it is difficult to get away with such fragrant breaches of ethical behaviour in the First World, and there are many, mostly smaller companies such as Napp who aspire to the highest standards of responsibility and probity, the pressures in a multi-million pound industry to behave otherwise are huge. Paul Schofield, Medical Director of Napp Pharmaceuticals opened our eyes to some of the pressures he has been exposed to both in big and small pharma,

¹ from his "author's note" at the end of the book, describing his sources of authentic material – well worth a read in itself . He "drew on several cases, particularly in North America, where highly qualified medical researchers have dared to disagree with their pharmaceutical paymasters and suffered vilification and persecution for their pains."

and Willy Notcutt shared his experiences of these in the development of a new drug.

The remainder of the conference was taken up with a variety of topics: Diana Brighthouse's description of the introduction of dynamic psychotherapy into pain practice led to a lively discussion on the nature of healing and it was decided that this and medicine as an art would be the main theme of next year's meeting. Andy Graydon suggested that we spend far too much time talking and thinking and led us into a deeper level of consciousness through silence and meditation. Paul Martin and Margaret Currie recounted case histories that raised as many ethical as clinical issues. Willy Notcutt took us through some ethical issues arising out of the prescription of drugs of potential abuse or diversion, and it was decided that next year time would be spent thrashing out a code of practice for the benefit of members of the BPS. (This proposal has been approved by the President).

The format of meetings of the Group is designed to maximise the time available for discussion. In general I have reproduced the speaker's words in "ordinary" print and contributions from the audience in italics. I have had to resort to a certain amount of paraphrase, abbreviation and guessing of inaudible contributions, and crave indulgence for any unintentional misrepresentation. Nor of course have I been able to record the hours of discourse in coffee room, pub and on the fells.

Peter Wemyss-Gorman

The Group is indebted to Napp Pharmaceuticals for their generous sponsorship of this meeting

Reflections on the joint declaration

Dr David Greaves, Hon. Senior Lecturer in Medical Humanities, University of Wales

Suppose people opened their papers one morning and saw “Pain Relief – a human right for all” they’d think “wow!” and that might be your reaction. What I’m going to do this morning is to help you to reflect on what that means.

Inevitably I’m going to appear as a grumpy old man concentrating on the negative but the purpose of the day is not for me to try to lead you to any particular answers but to get you to think about these things more by giving you one or two examples. Because you are all involved in pain relief you have thought a great deal about the nature of pain but perhaps not so much about human rights.

I would like to start by talking about a case written up by Cecil Helman, who was an anthropologist as well as a GP. concerning a patient he called “Eddie Barnett”, who seemed to illustrate the contention that by naming a condition and providing it with personal meaning Western doctors are engaged in a process analogous to healing in traditional societies whereby the healer exorcises the evil spirits of the illness. As Cassell observes “the doctor’s explanation connects the unknown and apparently uncontrolled phenomena the patient feels with the remainder of the patient’s experience”. Eddie was a man in his late sixties who made repeated visits to the surgery always with the same complaint of pain and the same doleful demeanour. He was obsessed with his pain which constantly moved around and changed character. No drug

gave lasting benefit and no test revealed anything significant. He refused all offers of psychological help claiming that it was the pain that made him depressed and not the other way round. Helman writes:

“consultations with him always left me with a feeling of frustration and exhaustion. He followed every suggestion that I made with another question, and then another question. Asking for more details about his pain only provoked more requests for help. He was insatiable - like an elderly bearded baby sucking desperately at an empty breast. Slowly, though I began to recognise that Eddie’s condition need not be interpreted in conventional medical and psychological terms but could be seen in a wholly different light by turning to anthropological accounts relating to spirit possession, and I came to believe that the way Eddie interpreted and described his symptoms suggested the persistence – in a Westernised, diluted form – of this ancient and pervasive mythology. He was embodying this belief system and acting out this metaphor at a largely unconscious level. The only regular ritual available to him was his weekly visit to his GP – to a secular healer in a secularised healing shrine”.

It was not that the “spirit” could be exorcised with any dramatic change in his condition, but that the authentic voice of his pain could at last be heard. So in accepting his pain as part of his total life experience, Helman came to regard it as the other half of Eddie Barnett, to which he could become reconnected. This made possible an

accommodation in which he could learn to live with his pain in relative harmony, and so be partially healed.

It could be concluded that the role of the physician is therefore not necessarily to hunt for disordered pathology, and if none is found to do an awkward dance of collusion with the patient around the notion of psychosomatic illness. Rather, doctors have an important role as experts in the process of helping patients interpret and make sense of their pain as part of their experience of the world. If you can do that you have done something really important.

I don't think the Declaration is concerned with this sort of pain at all, but about the dramatic "physical" pain of a heart attack or cancer or trauma. The introduction to this session in the programme raises the question of resources to deal with pain both nationally and internationally. The above chronic sort of pain is much more common than "dramatic" pain. It constantly recurs in GP surgeries and alternative medical practice, and psychologists will be very familiar with this sort of patient. We have to take account of the fact that that the term pain encompasses a whole range of kinds of perception and the Declaration doesn't seem to take account of this at all. The intractability of Eddie Barnett's

pain had nothing to do with availability of opioids etc. He needed to be helped to make sense of his condition, and it may not be appropriate to try to take his pain away at all. What Helman is suggesting is that he has been able to help this man to make some sort of accommodation with this pain which in some sense is the representation of the suffering in his life, and not pain in isolation. He seems to have done this simply by accepting his pain and not rejecting the patient.

The term psychosomatic is a peculiarly Western concept. Doctors in the West tend to think about three kinds of pain: physical which is the easiest to deal with, mental not quite so good, but at least we can send them off to someone else, e.g. psychiatrists or social workers; and then there's this awful group of people that don't fit either category, and they have the nerve to come along and tell you that they have a physical problem when it's quite obviously psychological – they are breaching the categories of mind-body dualism and that's why we describe them as heartsink patients who keep coming back and also why we don't want to have to deal with them. (I'm not talking about doctors in this audience, of course, but about 80% of doctors in general).

A Kenyan experience: setting up the Kenyan chapter of the IASP

Dr Minha Rajput, Foundation Doctor, Dundee

I take issue with the term “developing world”. I come from Kenya (I am of Indian extraction but I am a sixth generation Kenyan). Kenya has its skyscrapers, its stock market, it's gold. We describe Asia as developing and parts of it are but surely not all. I prefer the term “poorly resourced” as that is a kinder and more respectful term.

Professor Michael Bond originally suggested “a Cure for Pain for All” as the title of the Declaration but this was changed to “Pain Relief - a Human Right” as we know we can't cure all pain.

I am going to talk about pain relief in poorly resourced countries and Africa in particular and my experiences in setting up the Kenyan chapter of the IASP and the problems we experienced there.

Kenya is a land of wonders – its mountains, lakes and its people but oh how has it turned into land of woes. We can talk about overcrowding, about pollution, about epidemics of disease such as cholera and of course AIDS. But imagine yourself as a person living in Kenya who has pain, be it physical or emotional, whether due to trauma or disease including HIV neuropathy, diabetic neuropathy and amputation. Suffering is a damage to the integrity of the self which entails disparity between what one expects of oneself and what one can do. We often equate pain and suffering but this is not necessarily the case: we see pictures on TV of people

who have been bombed or something and are sad and crying; will taking away their physical pain solve all their problems? – obviously not. A brief anecdote: we were treating some people for pain in one of the camps last year and a man came up to me and said “we don't want medicine, we want food – an empty bag can't stand” So perhaps what these people need is a bag of rice rather than a packet of amitriptyline.

But I want to come back to the setting up of the Kenyan chapter of the IASP. This involved the university and other hospitals and nursing homes in setting up a meeting for various people to come and relate their experience of trying to treat pain. The key people who put the syllabus together were Dr Koff from Germany and Prof Patel from Nairobi University. We talked about physiology and pathophysiology, about function and dysfunction and what to do about some types of pain and touched on some areas of research. We gave our audience, who consisted of doctors, nurses, health visitors and paramedics (but no psychologists) a questionnaire, which so far as I know is the first in Africa specifically asking people what *they* think they need, instead of being told what they need by people like us from medically sophisticated countries.

The first question was “what do you understand by the word pain?” They mainly answered in terms of physical sensation and discomfort. Only one

person knew the IASP definition. We then asked about the most common aetiologies of pain. AIDS related pain topped the list which was no surprise but we also learnt that mechanical pain was a major problem and a study from Nigeria has shown that as a country becomes more developed the incidence of mechanical pain rises: in urban Nigeria back pain is common but not in rural areas where people are doing lots of physical hard work digging and carrying and so on. Does this imply that urbanisation and people going to cities to find work - indeed lifestyle in general - is a factor in the aetiology of pain? The other aetiological factors were trauma and of course cancer and the WHO is trying to do something about the latter.

The next question was "what kind of analgesics are available? We found that most people were using NSAIDS, antidepressants and anticonvulsants. Mention of the word morphine provoked consternation as there are penalties for possession of supplies of morphine beyond what one is supposed to have. When the International Narcotics Control Board asked every country for an estimate of their need for narcotics, they found that the figures submitted were an unbelievable underestimate because people were afraid to say. I came across a recent example of a doctor who flew out from here to Kenya to be with a relative dying of osteosarcoma in his last days. She found herself fighting with the nurses for Fentanyl patches. He had brain metastases and was confused and hallucinating but they refused to give him haloperidol. They didn't even have a syringe driver. All this in a teaching hospital - not a little place out in the

sticks. So is it a question of developing an infrastructure, or one of knowledge, attitudes and practice? You can build a big hospital but if you have staff whose ideas are twenty years out of date(dry comment from back of audience "you don't have to go to Kenya") I worked in this hospital when I was 11 and saw people lying on trolleys in pain and the attitude was "if they are capable of making a lot of noise they must be OK" To return to morphine: the knowledge is good but the attitudes not conducive to good practice. And furthermore bad practice is reinforced by the laws governing its use and the behaviour of the government who do not want to import sufficient supplies of the drug for fear of being seen in the wrong light. The amount of bureaucracy is unbelievable.

We then tried to ascertain whether if people weren't getting adequate pain relief from conventional Western medicine they were getting it from alternative, traditional sources, which in many ways is the most accessible kind of medicine. It turned out that 54% of or respondents had indeed used some form of complementary medicine. Later on I visited a Masai healer and heard lots of stories from him about how he treats pain. (Does one need a degree to treat pain?)

The next question regarded assessment and we found that a surprisingly large number of people are using some sort of assessment scale. The problem arises however that standard scales are mostly in English; how can these be used in the developing world where not only are languages different but people even write in different directions!? Even

people who are multilingual may only think in one language. There are different conceptions of number in different cultures, but using verbal scales may not be appropriate where people are reluctant to admit to bad pain for fear of offending the doctor. The question arises as to whom pain assessment is for? – is it for the patient's benefit or ours, to make us feel we are achieving something? Pictorial scales (smiley and sad faces etc which are commonly used in children and people with learning difficulties) may have some universal applicability. *(from the floor: people often find frustration with pain scales as they feel they cannot help convey to the doctor how bad the pain is)* I have observed this even in Kenya – people in so many ways are the same the world over. Another source of error is the therapeutic effect of the physician's interest in the patient, which may include assessment itself.

The next question we asked was “have you had any training in pain management?” about 25% answered “yes” but this commonly took the form of a single one hour lecture or merely observing the administration of some form of therapy – hardly what would be regarded as adequate in this country. So if we are going to provide pain relief as a human right how are we going to contribute to training in a country like Kenya? Should some of us be spending six months or a year in such activity? *(what is needed is basic education at the undergraduate level – only then will any sort of specialist training be more than just dealing with the tip of an iceberg)*

The final question was “what are the most pressing needs for the treatment of pain in Kenya?” Out of the list of money, training, time and awareness, training was clearly identified as the most important, and this and awareness were consistently rated above money. This may seem to contradict the assumption we in the developed world may make that developing countries simply need more money. So should we be concentrating our efforts on providing training programmes rather than financial resources? (but money is needed to fund training programmes and to put that training into practice) Is it therefore our expertise which is needed rather than our money? *(what you are saying is that we are in danger of behaving like the parent saying to a child with a problem: “here's ten quid – now go and sort it out yourself”)* Yes – perhaps we are the resource that these countries need? Training must involve changing attitudes as well as imparting expertise. This is very important but we must guard against seeming paternalistic. Although I had gone to a great deal of trouble when designing the questionnaire not to make it paternalistic clearly some people found it – and indeed any suggestion of a need of change of attitude - threatening and I had some aggressive responses and even downright rudeness, which I found very upsetting.

The people who came to this meeting were self selected as a group interested in setting up a Kenyan chapter of IASP. *(there is a very good precedent for this endeavour: when I was involved in obstetric anaesthesia we helped set up training courses in two cities to train other Russian doctors and once you have got a core of enthusiasts however*

small who are sympathetic to your aims and don't feel threatened then that's the way forward; the Pain Society can arrange for suitable people to go out and start training programmes which will then spread out) (Another problem is a generational one: once people have been in practice for a long time they get very fixed in their way sand thinking; you have to get people young but unfortunately it is the senior ones you have to get on board to get any thing going) This was very much my experience – I had my greatest difficulties with the Professor of Anaesthesia, and the medical students were by far the most enthusiastic group. (I have a friend who has set up a cancer charity in India and spends half her year teaching doctors and nurses there, but has found that there is little point unless she also can make changes at governmental level and a lot of her time is spent talking to politicians: and she will not allow doctors and nurses to attend her courses unless hospital managers and medical directors come as well, otherwise they go back to the wards but are not allowed to put what they have learnt into practice)

I do recognise the potential limitations of using First World protocols in a third World setting, and with so-called international guidelines which are often far from being universally applicable (although the WHO analgesic ladder does come close to this). But these people deserve as high standards of treatment as anyone else, even if we all

realise this isn't going to happen: where you live in the world determines whether you even live or die. In a country with a high incidence of AIDS-related neuropathy, which is one of the commonest causes of pain, should we be concentrating scarce resources on prevention? Up to about three years ago there was much difficulty with getting official recognition of the reality of AIDS, and even now when it is much more accepted the cost of triple therapy is beyond most people and they simply die. Another reality is the fact that HIV disproportionately affects women, often due to rape, but women in Kenya, especially in rural areas, have no voice and no rights. Cancer is also of course a major problem but there is only one hospice in the whole of Kenya. (There are no pain clinics in Kenya. Although there are a number of unscrupulous doctors in the private sector who pass themselves off as pain specialists with negligible training there is nothing for ordinary people.) Despite the efforts of the WHO over many years there are still difficulties with morphine availability, although the recent EFIC conference has been very helpful towards progress in this area.

So pain relief as a human right is a very difficult and challenging concept. Can I express the hope that this meeting may be the start of some development – that we can bring together our good intentions and our driving force in some way which will be substantial and sustainable.

The wider responsibilities of pain practitioners in the affluent west

Dr Andrew Chmielewski, Consultant in Pain Management, Northampton

11th October last year was the First Global Day against Pain. The statements made by Sir Michael Bond that pain relief should be a human right and that now is the time to take pain seriously have been echoed in our discussion so far. The majority of people suffering unrelieved pain needlessly are in low and middle income countries where there is an increasing burden of pain due to cancer and HIV/AIDS. Limited resources should not be allowed to deny people access to adequate pain relief and palliative care which are integral to the right to enjoy good health. There are lots of special days devoted to various issues and these may perhaps be guilty of trivialising some of them. A global day against pain may not move the earth but it should at least focus attention on what we should be doing. The IASP's statement has attracted some cynical comments from those who believe that charity should begin at home. I saw a particularly venomous one on the internet in which the writer said that declaring pain relief to be a human right "was a typical example of human rights gone awry..... all these individuals want the West to pump money into Third world countries to pay for some kind of universal healthcare system these socialists think the industrialised world can afford such a thing when we already have a whole skew of problems of our own" This seems to reflect a fairly common attitude in the general public. Thinking about this sort of thing – this

is after all an ethical meeting – we do have to admit that we have our own problems. A story appeared in the New York Times last October at about the same time as the Declaration which related to a Dr Frank Fisher of California who was arrested on a charge of drug trafficking based on records that he had been prescribing high doses of narcotic analgesics. After five months in gaol and loss of his home and practice, he was released and told it was all a mistake. So although narcotic availability is a major problem in developing countries – around 1% in Kenya and 7% in Asia - even in North America and Europe we are not able to access narcotics as we should and as a pain clinician in this country I still experience difficulty for instance in prescribing Fentanyl patches.

To turn now to India. In India there is no free state health system; although what you pay is not often exorbitant there is some restriction in that sense. India is partially developed and there are gross inequalities of medical care. There are an estimated one million people suffering from cancer pain and as for non-malignant pain who knows? – no-one has ever charted it. Pain clinics are a rarity. There is an Indian chapter of the IASP and some very good doctors who are doing sterling work but they are up against bureaucracy and the way in which it is all financed. Among these is Suprtec Sen, a very enterprising young Indian doctor who came to visit me and several other pain clinics in the

1990's. He told me that his colleagues were reluctant to send patients to his pain clinic as they preferred to hang on to them and collect the fees - a common experience in India so in a country with enormous numbers of patients in pain they are not getting referred to people who can help them. 80% of new patients attending pain clinics have cancer pain. India is the world's biggest producer and exporter of medicinal opium but they have some of the world's toughest narcotic regulation. To quote an Indian doctor: "we don't need a lot of expensive high tech gadgetry - just morphine and a few other not very expensive drugs are all that are needed and above all the recognition that pain relief is a human right". You do need the people with the skills and there are a lot of people with the skills in India but they are not given free range, support and recognition, which makes it very important that under the auspices of IASP they are holding their own national conferences. I was asked to give a talk at one of these on recent developments in back pain but what was even more unnerving was sending a whole day in theatre doing various blocks mostly on people with cancer pain, without the appropriate agents such as alcohol, with a video link to an audience of 200 people in an adjacent lecture theatre, having to answer questions at the same time - very gruelling! They did make up for it with hospitality but what made it worthwhile was that they found it helpful and in particular that someone from a developed country was giving them the support they needed. One rather disturbing thing that cropped up was that Supratec Sen (the secretary of the National Conference) who has been running a pain clinic for more than ten

years asked me for a reference for a job in Britain. I spent a lot of time trying to talk him out of it : here was a guy with enthusiasm and drive but who wants to come to Britain to find a better life for his family. But surely he is precisely the sort of person that needs to stay in India to improve pain management there. It transpires that Britain is sending invitations to doctors in India and other countries to come and work in Britain, which I think is scandalous, and Paul Miller, the new chairman of the BMA, has recently publicly stated the BMA's opposition to "poaching" doctors from medically disadvantaged countries.

Next, the Lebanon. I worked in Biblos, which has been continuously occupied for at least 5000 years - reputedly the oldest such city in the world - and is mentioned in the Old Testament. It was the home of the seafaring Phoenician people. It has both ancient ruins and a modern city. Back in the 1940's, Lebanon, and Beirut in particular, was known as the Jewel of the Mediterranean. It was very rich, and a favourite destination for the wealthy in their big yachts. It then of course fell victim to the very long civil war and remains war-torn and struggling. But it is recovering: although you can still see bullet holes in the walls there is a huge rebuilding programme. It is relatively affluent compared to India and tiny - its population is only about 7,000,000 - which brings some advantages: India has an enormous infrastructure and great problems of communication and control. I went there in 1999 officially to give a lecture and finished up once again doing blocks in theatre. A typical patient had to travel a long way to the hospital, and his visit would be paid for by the family. You could only see him

once – there was no opportunity for follow-up. Compared to Calcutta the theatre was well equipped with an image intensifier that worked well. They are building a new big hospital with a major cancer institute and I was asked to help design the pain clinic there.

To conclude: I think we all agree in principle with the proposition that pain relief is a human right – at least up to a point. But it has to be taken in context; we also agree that freedom from poverty and hunger is also a human right, and pain relief cannot necessarily take precedence over these basic needs: where you have limited resources these have to be prioritised and indeed rationed. We have a responsibility towards developing countries because we are in a privileged position. We need to encourage pain doctors to come here for training, and we need to visit them, not to check up on them but to give more impetus to what has already been established. We need to participate in their national meetings rather than expecting them to come to our national and international meetings. To give the IASP it's due it has done a lot with schemes like sponsoring doctors to encourage them to start up clinics; there are chapters in most countries now and I think that is really what IASP is for. EFIC is also looking beyond the boundaries of Europe. I would suggest that when we retire we should consider spending substantial periods of time abroad to share our experience before we begin to vegetate and that this should be made easier – and of course this doesn't only apply to pain – which would go a long way to provide the skills and manpower that poorly

resourced countries need. Otherwise I fear that things will only get worse.

What mechanisms or channels can one exploit to facilitate this sort of thing? When I retired I thought it would be a good idea but although I had a few interested responses to letters I wrote nothing ever came of it. Should something be set up?

I believe there are agencies – I am planning ahead and have made contacts for instance in Nepal – you can't pick and choose where you want to go and there are other forces at work directing you – but maybe there should be some sort of network or organisation which would respond to people's applications...

Perhaps there is some hope that Douleurs sans Frontières which at present is a purely French organisation working only in francophone developing countries may become truly international like MSF

Maybe IASP should take this up

(Minha Rajput) It is my ambition to take retired doctors to Kenya. The IASP SIG for pain and torture may become involved – after all many of the problems in developing countries are post conflict – maybe to enable people with the experience, skills and above all the time

But is it really appropriate for pain doctors to go out and teach fancy techniques when all that is needed is to make morphine more available and teach people how to use it – do they really need specialist skills such as ours?

In India the number of doctors in the business is very small and could be augmented by people like us – its not a question of taking over and telling people what they should be doing – I'm not thinking of high tech – I'm keen to start with the grass roots – it would be as much for my benefit as theirs.

Even in this country we come across problems associated with cultural attitudes to pain and barriers to its relief and it is no use doctors going out to teach skills unless these difficulties are faced and people's attitudes addressed and patients and their relatives reassured, for instance about morphine; one might make matters worse.....

I'm not saying that what I'm suggesting would solve all problems – just that it would be one way forward

I think that in Kenya professions allied to medicine such as clinical psychology, physiotherapy and rehabilitation could make more inroads as on the medical side are more likely to meet resistance from doctors there. I met an anthropologist who said that people from primitive cultures should be left to deal with their own pain: they undergo rituals such as circumcision without anaesthetic which are supposed to encourage a positive attitude to pain and build character. Maybe the clinical psychologists could come in here to influence attitudes...

But I hope that there wouldn't be a tendency to over-medicalise pain problems as we have here. The sick role may have positive benefits within the family – have you seen this?

Most of the patients I have seen while working abroad have a much more trusting and receptive attitude to their doctors than is often the case here – much like my experience as a teacher in Africa – people want to get better and the placebo effect is strong – there is minimal responsibility on the doctor as they give an injection or a drug and don't see the patient again. The family and the extended family is indeed extremely important and you can utilise that – they share much of the responsibility for getting drugs and equipment and so on – including blood for surgery.

I wonder if there is a presumption in resource-poor countries who aspire to the standards of resource-rich countries that we have it right for their culture, and a presumption that we have something they want: and perhaps what we have is not just the expertise to perform celiac plexus blocks or whatever but also a broad education and a creative way of thinking and the first thing we should be asking when we go out there is what have you got that I can help you build on and not what we are bringing.....

I quite agree – what you find you have to do when you come to a new country is to spend time understanding the culture and in particular the medical culture – sitting down and listening first – and probably more than setting up some thing one should be thinking of helping someone who is there already – saying I may have something that may be useful to you but only you can apply it

I have recently worked with some Indian nurses here and their understanding of

pain theory and its application was far better than that of most of our nurses – we can often learn from each other

Humility is required!

When designing the questionnaire for Kenya I spent hours looking for a template that would be applicable but found nothing appropriate – perhaps it would be useful to design one that could be modified to suit where we are going so we can ascertain what they are all about before we start telling them what we can offer...

I sometimes think we need this sort of thing in pain management programmes to send to orthopaedic surgeons!

The same sort of exchange of ideas and meeting people with a different mindset could take place within Europe: there was an arrangement between the medical schools of Hanover and Swansea and although the Swansea end was always fully subscribed no-one ever made the return visit to Germany. My experience of coming from Germany was that took me years to fully adjust to a different medical culture. Maybe we should encourage people to come to groups like this where we can establish friendships and learn to understand one another.

Unless the other side starts looking you are wasting your time trying to connect. I was told in India that there were 300m Indians (about a third of the population) who wanted Western-style medicine -

and why shouldn't they have it? - we have it – but that 300m are taking up resources which could perhaps better be used for the whole population; how do you cope with that?

One consequence of the demand for Western medicine is that skills in traditional medicine such as the Aruvedic system are in danger of dying out – and although of course in many areas such as acute trauma Western medicine is of course superior they are very important.. The WHO is encouraging studies in traditional medicine to try to validate therapies that are useful but in these days of international big pharma where is the money going to come from? And going back to culture even though I was born and brought up in Kenya going back after many years I had such difficulty in readjusting and felt so alienated that on my return journey I was assailed by doubt that I was trying to do the right thing.

We have a large Indian population in Southampton and I find that over half the Indian patients coming to my pain clinic have tried Aruvedic remedies first.

Three further questions: firstly how do we encourage able health professionals in poorly resourced countries to stay where they are most needed instead of looking for a better life here? Secondly if we bring people here to train them what professional body is going to look after them when they go back? And lastly if we go out for a few weeks and do procedures whose patients are they – who takes responsibility for complications?

Post-amputation pain in landmine victims

Dr Peter Wemyss-Gorman, Retired consultant in Pain Management

I wanted to bring up this subject for several reasons: one is the sheer size of the problem; the second as it seems to be a classic example of deprivation of another's human rights: first we unnecessarily expose him to injury and then we fail to provide the means of relieving his suffering and the rehabilitation which will enable him to survive economically; and thirdly because I want to suggest that it may involve some of our wider responsibility that Andrew is going to talk about later.

First the numbers: in the last 65 years, over 120 million mines have been spread in an estimated 80 countries. Between 15,000 and 25000 people a year are maimed or killed by landmines, and an estimated 800 people die every month from landmine related injuries. 80% of casualties are civilian. 20% are children under 15. It has been forecast that by the end of the decade there will be at least 250,000 landmine related amputees. In the USA there is 1 amputee per 22000 of the population. In Cambodia the figure is 1 in 236. Very few of these will not have experienced some pain and 30% have pain sufficiently severe to prevent wearing of a prosthesis.

We have all, I think, found treating amputation pain challenging but often rewarding. The vast majority of landmine injuries occur in regions without sophisticated medical resources and it is estimated that only a quarter of amputees receive appropriate care.

There are two major components of appropriate care: pain relief and rehabilitation, including provision of prostheses. In many cases the latter depends very much on the former. Douleur sans Frontieres, the Lille based organisation which has done much valuable work in promoting appropriate pain management in the Francophone developing countries, have found that phantom pain responds well to TNS, which may even be more useful than analgesics, especially morphine which may be of restricted availability. There is some doubt regarding the efficacy of TCA's, but Paul Lacoux and his colleagues found the combination of amitriptyline and carbamazepine cheap and very useful in treating phantom pain in Sierra Leone, though he wasn't actually treating landmine injuries but working in the even more gruesome context of punishment amputation. Ketamine may have some pre-emptive value, and is used widely as an anaesthetic in the developing world. DSF have also found neurolytic injections very helpful in stump pain, especially where the latter prevents prosthesis wearing. The relevance of all this to today's discussions is that much can be achieved with relatively simple and cheap measures which can easily be taught to local health personnel – but by whom?

The US based Centre for International Rehabilitation have identified two main problems in providing rehabilitation in low-income countries. Firstly the cost of prostheses: although there are excellent low-tech designs which can be made

locally and which only cost some \$40 the life time costs for replacement and maintenance of these will amount to thousands.

The second is the lack of trained personnel, and training institutions for these. It has been estimated that although at least another 50,000 prosthetists are required it will take 30 years to train just 18000 at present rates. Physicians Against Landmines (PALM) have come up with the figure of \$750 million to cover the medical expenses of current landmine victims, and these are added to every day. But rehabilitation is essential not only to reduce the overall burden of suffering but in enabling these relatively young people to work if they are to survive in poor societies.

It is an axiom of all modern medicine that prevention must if possible go hand in hand with treatment, and is even more important in conditions for which there is no cure. Reduction of landmine injuries by reducing the numbers of landmines bring used and clearing those that are there is an obvious priority. But the problems are massive and almost overwhelming. The Ottawa Treaty of 1999 has not yet been ratified by many countries including the US, Russia, China, India, Pakistan, Finland, Poland and Latvia. As well as the continuing deployment of antipersonnel mines, so-called Explosive Remnants of War, including Cluster Bombs (which are not covered by the Ottawa Treaty, and used by the UK in Iraq) pose an additional huge problem. Clearance is of vital importance but is a slow and dangerous business and it has been estimated that to clear the 120 million

mines lying buried around the world at present rates will take a thousand years (in Croatia alone 690 years.)

So what should our response be to all this? The temptation with such an apparently overwhelming problem is to bury our heads in the sand and ignore it, or if we do think about it too much to be reduced to a state of hand-wringing impotence. Or we can simply dismiss it as someone else's problem – after all there are no landmines in Britain and we have difficulty enough coping with our own clinical challenges. But if we believe with John Donne that no man is an island perhaps we do have global responsibilities? Most of what needs to be done is on a political level with a need for a massive increase of governmental support for organisations such as the International Committee of the Red Cross which has done much of the research quoted earlier and much of the work towards for instance training of prosthetists, and for the mine clearing organisations (in particular research and development of faster, safer mechanical methods) as well as untiring efforts to achieve at last a universally accepted ban on the use of these weapons. As individuals we can support campaigning organisations such as Landmine Action in their lobbying activities towards these ends. The IASP have taken the problem on board and an excellent survey of the subject in Pain, Clinical Updates in 1998 concluded that “the crucial yet unmet need for pain control among victims of landmine injury must now receive the attention of pain specialists worldwide”.

Where do we stand?

Comments on morning's discussions

Dr David Greaves

The important point to be made is that the best way to make improvements is not simply to maximise the physical and spiritual resources according to which was deficient in each case, but rather that these resources are not separate and therefore additive components, but form an interactive whole. Thus the aim in providing what is best through ever-increasing physical and spiritual means is neither coherent in theory nor desirable as a goal. Developing countries would unquestionably be better off with more and more readily available technical resources but if they are not introduced as part of their culture their overall effect may be damaging. Some cultures remain sufficiently strong and coherent to prevent this happening. For instance it is said that Swazi culture easily assimilates biomedicine into the traditional idiom of illness and healing, which being based on a traditional idea of learning and knowledge, is given a place like herbalism, next to but morally inferior to divination! This contrasts with India where there is an aspiration towards regarding the West as somehow superior to what is culturally indigenous, and this is a very serious matter. Equally, developed societies cannot readily improve their spiritual resources as a matter of public policy or through private provision, although this is where most attention is required. Even the hospice movement, which has made an explicit attempt to address spiritual issues in relation to death, can only

hope to make a limited contribution in this respect because it has been grafted on to British culture rather than becoming an integral part of it. It is the physical and spiritual culture as a whole that needs to change, and aiming at sustainability by placing limits on material consumption and technical solutions would be as a good place to start in medicine as anywhere else.

So let me briefly draw out some conclusions to think about. In developed societies we have no cultural or religious framework within which to comprehend death. Up until a hundred years ago we did but not now; we may still talk about religion and spirituality but they are no longer deeply embedded in the culture. What I therefore want to claim is that if we were to provide the same services in Kenya as in Scotland – all the drugs and technology needed for pain relief - probably we would have to change that society as a whole and make it more like ours in order to be able to deliver all those things. And if we did that it seems to me almost inevitable that we are going to undermine those very strengths which we've lost. The story that Minha told about how in Nigeria attitudes to back pain have changed between rural and urban society seems to illustrate this very well. It isn't just that when people move from rural to urban areas they do less work than they used to but it's about the whole of life and a change in world view; and it is a change to a fun-

damentally Western world view of urban cultures that work in a market place which is global. If they take on that culture they may get all those technical resources but they may at the same time lose those religious and spiritual resources that are culturally embedded in their society in a way that enables them to cope with suffering and death in a way that a lot of people here can't.

So what can we learn from that? I am not of course suggesting that we should do nothing for third World countries at all. Only last week I was reading an essay by a philosopher called Anthony Grayling about bystanders, saying that in the 21st century there are no bystanders; even the most remote Amazonian tribe is somehow touched and affected by people in the rest of the world, in cultural and economic exchange, in political ideas, health, medicine and everything else so that we can no longer pretend that we live in isolation and have no responsibilities. But we have to be very careful how we institute and carry out these responsibilities, and I have listened with great interest to what several people had to say about this this morning. The lesson which I take which maybe hasn't been so much touched on is that there is a real problem with looking at pain in isolation rather than looking at suffering as a whole – that is the Western, reductionist way: you break everything down and deal with specific things in a specific way, rather than looking at the whole picture. Human rights are based very much on ideas of individualism: they fit in very well with the reductionist view of individuals having reductionist problems and which therefore have technological magic bullets to deal with them or even psychological packages

which can be designed to hit the spot. The TV programme “spiritual shopping” in which people with problems are helped to find some sort of spiritual quick fix from a shortlist of four religions or whatever seems to say it all about this sort of attitude! So we have to be very careful about imposing ideas like individualism on countries like Kenya where they can be extremely detrimental and negative. But there are positive aspects of human rights: it has been described as raising the political profile, like someone shouting “there's a problem over here – you ought to be doing something about it” That is good but the trouble is that it tends to reinforce priorities that we already have in mind and leave behind other priorities. We all know that the things that will really get people going are those like children with cancer, and if you pick the right sort of issues you're going to do brilliantly. But what about the other pressing issues – how do they fare? We all have to be aware of this.

We really do need to learn from societies we call poorly resourced (although this is probably anathema to many people) as they are often not poorly resourced spiritually as they are economically. And the corollary of this is that perhaps we need to spend *less* money on health care. In the USA they spend 14% of their GNP on health care; we spend 7% (Tony Blair is committed to getting up to the European average which is currently 9% but it keeps moving upwards and I doubt if we are ever going to reach it) So where is this going? It seems to me that a lot of the problems are generated by the culture – they are not inherent physical problems. When we talked about needs when the NHS was first set up we were talking

then about something completely different: it was perceived in a very simple way that there are some sort of universal basic needs and that people had fixed problems and there were fixed solutions to deal with them. Health care is a very strange animal: it's not like planning a holiday abroad when you think "if I spend this much money and go to this place I will get that amount of

enjoyment". Health care has been described by economists as "wonderfully inflationary": the more you have the more you're going to need, and so to a degree we create our own health care problems, like the people who move from rural to urban Nigeria. The epidemic of chronic pain we see is largely a product of our culture.

Rationing pain management: should we ration our care to those most likely to benefit? Will this infringe the human rights of those patients no longer catered for?

Dr Ian Yellowlees, Consultant in Pain Management, the Borders

Let's leave aside for the moment consideration of the morality of Western medicine and assume that we are going to spend silly amounts of money on treating pain for a few lucky people in Northumberland. Generally in health we all agree that resources are always going to be limited and however much money you have it is never going to be enough. The question is what to do with it?

The way I see it is that there is a reasonable amount of evidence that in pain if you intervene early enough, in the window of opportunity, you get reasonable results; if you give a bit of temporary pain relief, to help with physiotherapy and exercise, and if

necessary psychological intervention, you can prevent people going chronic; and up on the Borders we dramatically reduced the number of patients going on to orthopaedic surgeons (an unwritten aim of the service!!) But the evidence for the efficacy of any late intervention is awful, and if managers asked for figures to prove that your pain management programme was of any benefit in the long run you'd probably have to say "fair cop – you'd better close us down". This isn't to say it doesn't do any good, but the evidence for it is pretty thin. The book brought out by the Pain Society and the Royal College of anaesthetists on best practice in pain management is using data from years ago. And secondary

care is just the tip of the iceberg; most of the work is in primary care.

So when I started to think about pain relief as a human right I decided it ought to be something measurable so we know whether or not we've done it and given people their rights. So what is this pain relief that we want to be a human right? Most of us Western doctors will talk about the biopsychosocial model of pain and the IASP definition and all that stuff. Is it something measurable by VAS? - or more to do with quality of life? Most Pain Management Programmes explicitly say they're not there to provide pain relief – a bit tricky really if you're offering a service that explicitly says we are ignoring your human rights!

So what to do about it? The longer I'm in the pain business the more I am aware that dealing with the long-term chronic pain patient uses up a huge amount of resources. So as a philosophy do we subscribe to the idea that we should be trying to do the greatest good for the greatest number (assuming we know what that good is) or should we be doing something much more measurable? Perhaps we should define YIPS – Years in Pain Saved like QUALI's) And what about temporary measures like facet blocks: should it be our patients' human right to have a facet block every three weeks as they get three weeks' pain relief?

So what are we to do? What I am going to do now is to break you up into four groups of six or so to answer some questions I am going to put to you.

(the following are reports from Groups:)

Pain is a sort of disruption of self which has consequences like not being able to work, not being able to enjoy one's family or relationships and the object of pain relief is to return people to their previous state (one could question as to whether that is always desirable) Should we regard this as a human right? The question then arises: for example, if someone is suffering chronic pain due to a lifestyle that they had chosen due they have the same right as someone who is a victim of a road traffic accident?

If you confer a right it then becomes an expectation. Will there need to be legislation to allow people to enjoy their expectations?

We thought that all four components of pain: physical, psychological, social and emotional – needed to be present

So what about someone experiencing psychological pain without physical pain?

We conceded that to make the definition this wide would have huge implications in terms of resources.....

So we're talking about something we can't define or measure

So here's the next question: can we abandon the people for whom pain relief would be either impossible or at least very resource intensive? And if you decide that we can, how do you manage the political fallout? And if you decide that we can't, what

consequences does that have for services?

We were divided on this.... Some of us thought we had to do the greatest good for the greatest number, and others that pain clinics were there to treat chronic pain.....

There comes a time when heartsink patients for whom there is no coherent strategy have to be told there is no easy answer – there is no point in doing anything else because its not going to work – you're not rationing them, and we would explore all the possibilities right down to the bitter end, but it would not be honest to give the patient the impression that there is anything more we can do

We would get to a point of recognising that we have limited resources that if we spend all our money on someone we are not getting anywhere with we are denying someone else. So we might need to deny someone in that sense but we didn't like the word "abandon" in the sense of "clear off from my clinic I don't want to see you again" ... we need to look at alternative strategies for moving people on, perhaps back to their GP, or perhaps the very occasional visit which is low cost and perhaps will prevent people from going round the roundabout of orthopaedic surgeons and investigation again – which will save money. Sending them back to their GP with the lifeline that "I will see you again if things radically change" may be useful.

We had a patient recently who wrote to their MP because their GP had been treating them with acupuncture but retired and passed them on to the pain

clinic for the same thing but we couldn't continue this indefinitely although it was the only thing that helped his knee pain. I had to be honest and say this was a resource thing..... I thought he would be a very angry man but he wasn't – and perhaps there are containment strategies....

Does anyone think the voluntary sector has a part to play?

We didn't like the word abandonment to describe discharge from the chronic pain clinic – we wanted people to know that we would continue to be beside them ... We tend to think that the only people who can help patients in chronic pain are pain clinic doctors but of course that isn't so – there are a lot of people who can help patients to do what they want and referring then in this direction may be helpful

So should our resources be aimed at preventing chronic pain or treating it?

Much of the prevention can and should be done at the level of primary care, which leaves our only function as treating chronic pain.

The way you organise your services is important - first of all I would say that the distinction between chronic and acute pain services isn't always clear and it is important to integrate the two so that adequate treatment of acute pain – for instance in the ITU – may play its part in prevention of chronic pain.

Having identified your groups how are you going to make sure that they are getting what you have decided is better

for them? How do you make sure that your skills are being best used?

We can delegate things like acupuncture and TNS instruction to other members of the team and educate GPs in the use of certain drugs.

Are these things..... not human rights like pain is? If not can we have their money?

Education is an important resource.

Speaking as GP I would like to see much better integration of primary and secondary care; my patient not having to wait six months for an appointment and me having to wait weeks more for a letter – I want to know when I have a patient who wants to work but can't because of the pain how I and the pain team can work together to help him – and my strong impression is that the less time waiting for this the more we can achieve.

We found it difficult to identify other models – anything different from the usual pattern of referrals from primary to secondary etc etc. Perhaps it isn't up to you to choose a model: you for instance are working within Northumberland's health care model so all you can do is say thank you and go away and use the money as efficiently as possible.

Can I demand more money because pain relief is a human right?

Should I take the health board to court for failing in their duty? – for failing to provide an ethical distribution of care?

Pain relief has always been the Cinderella of health care – does the declaration mean that Cinderella is about to go to the ball?

Patients don't speak loud enough – there are pressure groups for cancer and heart disease and diabetes but are chronic pain patients properly represented?

Pain isn't seen as a chronic disease like these things and perhaps it would get a better priority if it was.

Pain is seen as a symptom and not a disease and people are going to say that the right should be to treatment of the cause rather than the symptom.

In law you can get large compensation for pain and suffering.

We seem to have been handed a big political card [by the Declaration] but are we a bit dubious about playing it? Wouldn't it be not very ethical if we are taking resources from all these other deserving things?

One thing that distinguishes pain from these other conditions is that it usually involves time off work, so if we can link what we do to getting people back to work then that represents a good investment and a good economic justification for directing resources to pain

But that's nothing to do with human rights

If we don't use the declaration in some such way what use is it? Indeed is it any use?

What I have been trying to do is to show that we are inevitably constrained by reasoning of finite resources, and I think it is beholden do us to think about how we structure our services and the evidence for what we do and to be fair, the

evidence for what other people do; should we really be seeking to take money away from things like diabetic management that we know work? These issues are very complex and rarely looked at a fundamental level.

Conclusions

Dr David Greaves

It's been fascinating listening to the group grappling with these questions and to see how quickly one gets into deep philosophical water. It's said that everyone does philosophy down the pub at night but professional philosophers go on doing it next morning!

In his book "The Culture of Pain" by David Morris (University of California 1991) Morris takes the issue of the relationship between the "objective" and "subjective", as represented by the "physical" and "mental" aspects of pain, to be central:

We live in an era when many people believe, as a basic, unexamined foundation of thought – that pain comes divided into separate types, physical and mental. These two types of pain, so the myth goes, are as different as land and sea. You feel physical pain if your arm breaks and mental pain if your heart breaks. Between these different events we seem to imagine a gulf so deep and wide that it might be as well filled by a sea that is impossible to navigate ... one main purpose of this book is to begin to collapse the artificial division we create in accepting a belief that human pain is split by a chasm in not uncommunicating categories called physical and mental.

After considering these issues at length, Morris suggests the following analogy:

We might represent the Myth of Two Pains as two closed fists. Now imagine that the hands are open and the fingers interlaced. Pain, especially chronic pain calls forth some such interlacing of mind and body. It is physiological to be sure. But as Richard A. Sternbach was arguing as far back as 1968, the physiology of pain is also powerfully adjusted by broadly cognitive influences such as *meaning, emotion and culture*.

This raises the possibility of a "psychophysiological" reaction which, as Morris notes, Sacks had already proposed in his work on migraine. What both these authors are raising through this integration of physical and mental is something quite different from the more customary notion of "psychosomatic" illness. This term tends to be used as another means of subordinating the "subjective" psychological aspect of medicine when it does not appear in a conventional manner by being clearly separated from the physical.

Now a brief sketch of some history and philosophy. The whole of our modern way of thinking, put simply, begins in the 17th century. The ideas of modern

Western science and the ideas that have formed the traditional medical model – the biomedical paradigm – have their origin in the 17th century. Descartes has become our favourite hate figure for dividing us up into minds and bodies; it is a very complex matter to describe what Descartes was really up to and we haven't time to do this today, but he was one of the people who were setting the agenda for modern Western science. Descartes like many of his contemporaries was interested in knowledge across the board – he was interested in the body and did dissections. His theory of pain, the “rope pull” model, was the dominant influence on the organic or biomedical model of pain for two centuries; he saw pain as a *sensation* which automatically travelled in nerves (which he knew about) until it entered the brain through the pineal gland, his conception being that the mind and body were connected through the pineal. It was the whole basis of reductionism that supplied the idea that we can think of pain as something out of context, as something separate, as something that *happens* to an individual.

Now the new models which have emerged in the second half of the 20th century are not viewing pain as a sensation so much as a *perception*: an experience in which consciousness, emotion, meaning, and social context all play an important part. It is much more complex than the simple mechanical model of Descartes and involves feedback loops and a sort of playing backward and forward between mind and body. This is why pain can appear in so many different strange ways – and sometimes not appear, such as in “silent” heart attacks: what is normally associated with excruciating pain may

not be accompanied by any pain at all with exactly the same pathology. This on Descartes' model should be an impossibility.

Engel said in 1977 that he regarded the biopsychosocial model as scientific, allowing the possibility of not only quantifying biological matters but psychological and social ones as well, which is quite different from adding those things on.

The concept of human rights emerged as an Enlightenment idea in the 17th and 18th centuries. Thomas Helper wrote of “Positive Rights in a Republic of Talk”, and the seminal work on the subject was Thomas Paine's “the Rights of Man” published in 1791. Such ideas heavily influenced the development of the welfare state up to and after World War II. This was based on the concept of *social* rights and needs – a collective idea. There has however been a gradual change over the years towards regarding human rights as an individual matter, starting with the 1948 UN Declaration and typified by the WHO/IASP declaration on pain. This trend in thinking has affected life in Britain in many ways since the 1980's.

There are a number of problems associated with the concept of Human Rights. The first of these involves individualism – the right of the consumer to his share of commodities in the market - and the difficulty of applying this to pain relief as if it were some kind of commodity.

The second is that of legalism: the assumption that rights can be codified in rules and somehow enforced. But if we say that there are all these rights,

then someone somewhere has an obligation to fulfil them, otherwise they are empty – so in proclaiming human rights you are trying to make someone have an obligation; but what if you can't? What tends to follow is that if you go all the way down that road you finish up with every one wanting to go to court to establish their rights. Things are going that way in Britain; they have gone much farther in America and we seem to be following them.

Let me now make a very important distinction between what one might call *positive* rights and *negative* ones. Negative rights are the sort of thing that Thomas Paine seemed particularly concerned with and are not so much about obliging anyone to *do* anything but rather as rights to be left alone, such as liberty and free speech. We use these, for example, in the instance of the foetus's right to life, to maintain which entails *not* doing something. But things like *right to life* can be very confusing as they can also be interpreted in a positive way: not only do I have the negative right not to be killed as a foetus or by capital punishment, euthanasia or even being sent off to war, but people are now saying I have the positive right to have every thing done at the end of life. Someone else has to put me on life support and I have the right to demand that. Well, we haven't yet gone quite that far in Britain and even in the States they are reluctant to do so; the legal position in England and Wales – and there have been cases brought to court - is that judges will always say "is this is a matter of priorities? – if so we don't want anything to do with it". They recognise that trying to fulfil the rights of some may have to entail prioritisation

of demands, such as between cancer and paediatrics, or between acute and chronic medicine. But some people still feel that their rights allow and encourage them to keep on pushing and pushing to make more claims.

The other thing the idea of rights does is to tend to dispense with the professional definition of professional negligence and threatens to put you all out of business, because now people come along and say all we want to know is how we can use all this medical information we can get off the internet in order to go to court, and there seems to be a small but increasing minority for whom all they want from doctors is to help them find their way around the internet and then demand that they do the technical things they have chosen from it.

So to conclude: firstly the bio-medical model of pain and the idea of human rights have a common lineage: they can be traced to the 17th century and to a whole set of new ideas emerging then, and as it were come out of the same stable which one might call the "Enlightenment Project". I would like to suggest that they also have a number of problems in common.

The trouble is that they are both based on the assumption that all problems are soluble. Pain is regarded simply as a puzzle to be resolved, rather than a mystery to be grappled with. Pain is seen as isolated, and as long as drugs and other technologies are made available for its relief, human rights will ensure their just allocation, and we can get them by claiming our rights. But suffering comes in many forms, of which pain is only one. Quantification of

it will always be problematic, and costs and benefits of pain relief, as we have heard, are frequently unclear. The puzzle may never be solved, but we must go on grappling with the mystery.

I would like to finish with three conceptions of health. When the Health Service first came in the very simple 19th Century biomedical model was still in place. It involves a negative definition of health as simply the elimination of disease. But at the same time the WHO provided a much more positive and holistic definition: "Health is *not* simply the elimination of disease and disability; it is physical, mental and social well-being". The problem with this is that of you go for such a wide definition it seems that health incorporates almost everything – even life comes into it! I'm going to give you a third definition which I like because relates to a wholly different context. It is based on the writings of an obscure French philosopher called Canquihem. French philosophers are notoriously difficult to read so I am going to quote from a paper by Kenneth Boyd which attempts to interpret the essence of what Canquihem was saying:

"Health is not a matter of getting back from illness, but of getting over and perhaps beyond it. To be healthy is not to correspond with some fixed norm but to make the most of one's life in whatever circumstances one finds oneself, including those which in terms of some fixed norms may seem severely impaired or unhealthy".

Simon Weston, the Welsh Guardsman who was horribly burnt in the Falklands war and who remains hideously deformed despite multiple plastic surgeries, has said that he feels

himself to be healthier than before that happened. What I think he meant by this is that his whole life has been so traumatised that he has come to a new understanding of what it is about.

You have to be very careful about romanticizing this sort of story as there are lots of people who have dreadful disabilities from dreadful events in their lives but they don't have such positive stories. It seems to me however that the idea of helping people get over and beyond disability is important. It changes the goal: it doesn't say "what we need to do in Western medicine is to sort everyone out, and if we can't sort them out to keep on and on trying" but something quite different: once we've exhausted the obvious technological possibilities, it is best to enable them to make the most positive fist of their lives. That is a much more modest goal, but if we could all inculcate it into all of our minds and those of the public and politicians it would go a long way to dealing with the issues we have been talking about.

Lastly may I make a plug for my book, "The Healing Tradition: Reviving the Soul of Western Medicine" in which I make a lot of these arguments in the round, and not specifically with regard to pain.

To take up your point about people changing their perception of themselves: in palliative care we deal with a lot of patients with motor neurone disease and other progressive neurological diseases. They come in for various therapies but there is a big element of social interaction between them and it is very interesting to see how the group work. After two or three

months they have shifted: you haven't changed what is going to happen to them – they are all going to die in a few weeks months or years but their perception of themselves has changed. For instance we had a young man with Huntingdon's disease; when I first met him his wife was about to leave him and he had had several suicide attempts but after a few weeks in the day unit - which he didn't want to come to - he has come such a long way; he realises that he doesn't have as many problems as some of the other patients; he and his wife still have a dreadful journey to make together but they are coping with it.

I have a feeling that the hard nosed biomedical approach is a historic aberration; its only Western society in the last 200 years that has gone down this road – no-one else has – Indian, Chinese and other traditional systems are basically humoral as was ours. But attitudes are changing: it is why you have a philosophy and ethics group which has just been recognised – these things are being questioned more and more and it's why you are here today; but these questions are being asked from underneath and there are still those guys – who aren't here - who still believe that evidence based medicine is everything and that there are magic bullets. The latest is genetics, and incidentally the Wellcome Trust have a budget of 11 billion pounds for genetic research. They have expressed an intention of getting into in ethics but only *after* the research has been done. The whole point of moral philosophy is to question everything - not to say we carry on as we like first - but most recent ethical debate has been after the

event; like when we've done everything we want to do then how do we share the resources? – not should we be doing these things in the first place.

Can I bring up palliative care as a model of health care: in palliative care it is acknowledged that one of the functions of the carer is to witness and be alongside in the experience of approaching death. There are also people using the quantum physics model: everybody is a wave; the therapist and the patient come together, there is an interaction and both are changed.

Medicine always lags behind pure science; over a hundred years ago scientists recognised that if you observe something it changes. In the reductionist health model every thing is static, but in the new model because patient and therapist are constantly interacting and changing each other things change all the time. This could lead to the unfortunate conclusion that if things are changing all the time we can't do anything at all but I believe this is wrong. What we need is a return to *reason* which acknowledges this changing – not rationalisation which has a fixed endpoint – and which was wiped away by the Enlightenment project. We need to return to the past but interpret it in the light of all the wonderful things that have happened since. A practical implication of this interaction came up this morning: if you have very poor countries and very rich, scientifically advanced countries, and we recognize that the former may be materially poor but are spiritually rich, how do we help them in material ways which don't downgrade the spiritual?

Ethics of the drug industry

A view from both sides.

Dr Paul Schofield, Medical Director, Napp Pharmaceuticals

To explain my title: up to 1998 I was a consultant physician in Cambridge also doing research into gene therapy. As an academic clinician I was interested in bringing science to the bedside but I seemed to be getting further and further away from this and my clinical and laboratory lives more and more separated. The providers of funds such as the MRC and Wellcome seemed only interested in basic rather than clinical research. Then a series of tragic events in the US put the whole topic of gene therapy in jeopardy. These included a young man in Philadelphia with a rare liver disease who was injected with a very large dose of adenovirus and died. (It turned out that the guy treating him was very closely financially linked with industry and perhaps had a vested interest in success.) With that background funds began to dry up in the UK and it was regarded as a very high risk area with low returns. So when I couldn't get funds from the MRC I turned to industry. Smith Kline Beecham had supplied me with some basic lab equipment, so I knew them and they offered me a job in experimental medicine testing new drugs at the bedside. So in 1998 I went over to this, at first keeping my clinical interests going.

I was interested in coming to this meeting as nearly every day as a physician in industry I am confronted with an ethical issue. In Phase 1 trials, for instance, I had to decide about recruitment and payment of volunteers,

whether it was ethical for a trial to go on and so on.

Drug research is very expensive. There are champions to contend with. The scientists have been doing five years' intensive work in the lab at a cost of some 20 million pounds, and then the project is handed to me to design and conduct clinical trials. What then happens if things start to go wrong at this stage – someone develops a dangerous arrhythmia, or someone else severe vomiting? The company then come to me as ask: is this really serious or can we carry on with the next dose? It's very helpful to have advice and guidelines from experts I'm working with so I can say "its not just me that has misgivings". Big companies can afford to invest in the real novelties and quite a lot get lost but the pressure is there; at shareholders meetings people are going to ask: what's your portfolio? – what are the chances of these molecules coming through – and if the medical advisor is seen knocking them out before the shareholders' meeting he's not perceived as being very good for the company. There is pressure to delay starting or perhaps finishing a study until after the shareholders meeting. In big pharma's like Smith Kline Beecham (now Glaxo Smith Kline) with about 150,000 employees worldwide in whom 30,000 are engaged in R & D there are always people who will try to block you, your voice is very

small and you can be blotted out and they can carry on regardless.

The ethical situation was often very tricky – for instance there was one trial where the drug tended to raise the blood pressure so it was suggested that it would be best not to take the BP in case it was found to do so to a dangerous degree and the trial would have to be stopped - but I found it very difficult to have any influence. So when I was offered the medical directorship of NAPP which is a relatively tiny company, and has no shareholders, being privately owned by a philanthropic American family, I was very much attracted. I have moved from involvement only in Phase I trials and what I do now is much more concerned with the actual marketing of established drugs and the ethical questions I face daily are more to do with PR (like our sales force going out and being very nice and persuading people like Willy to be quoted as saying the right things)

So several times a week I am presented with ethical problems, either internal about what we are doing or external, about how we present ourselves. I am a paid employee of the company – I am fully in bed with them – but as an individual I have to decide what the principles are that I have to live and work by. I had never previously had to think about this so much, and certainly don't remember being taught anything about ethics as a medical student in Leeds; and there was certainly no requirement to know anything about them when I joined the industry. So I thought it was about time to learn something and enrolled on a course. It was very interesting but I needed something more than deontological ethics versus

utilitarianism and consequentialism and the like, in terms of the simple principles I needed for my everyday work and life. When the MD or someone comes to me and says: shouldn't we be doing this that or the other because and because..... and all the becausees are commercial and ignore clinical issues such as side-effects, I need to be able to give answers which don't compromise either my personal integrity or the company's. As medical director am responsible for advising my colleagues on the Board about ethical issues and will be responsible for standing up and defending the company if things should go seriously wrong. I need to be able, when people are pulling one way with considerations of profit and returns and shareholders to pull the other way and maintain the company's high standards.

To give you a recent example: a few weeks ago I was at a meeting on the advertising of a strong analgesic and it was proposed that the new strategy would be based on the image of a waste bin with a pill in it, and the concept was that the pill was saying "I was your analgesic and you've thrown me away but you'll want some more of me"; and people were getting all excited and saying how great it was and I had to say: "hang on a minute – you can't say that – it's unethical! We're marketing a strong opiate and telling people they had to be very careful how it's disposed of and not leave it lying around where children can find it" - and so on – and some people there were astonished. However they agreed with me but I reflected that had that been in a big pharma company that would have gone seriously against me, and there would probably have been another meeting to

which I wasn't invited where it would have been pushed through. That for me is the big advantage of a small company where I am the medical director and no-one can over-rule my decisions – they may question them and I have to explain my reasons but they acknowledge that I am the one who will carry the responsibility if things go wrong. The marketeers are a very enthusiastic bunch of people and get very excited about their projects but I (and sometimes the legal guys) have to be able to say “you can't do that” and they accept it. But they would much rather I said you can't do it that way but I can suggest an acceptable alternative.

It is very helpful when dealing with internal matters in the company that we have a code of business ethics that can be referred to if things go to the wire – in a very tricky situation that people have got fired up about - it isn't often necessary but I can say “this is what the Board, with consultation, have established as a set of ethical and moral principles that we and our staff will be held accountable to.” We have also established a set of core values which we will hold people to and reward them for such as displaying integrity, respecting individuals and their opinions, and supporting people and not witch-hunting. There have been papers on the ethics of whistle-blowing. There was a case that attracted some publicity some years ago regarding a subsidiary of Johnson and Johnson who sold substituted flavoured sugar water for the apple juice they were marketing when the price went up of the natural product. Everybody in the company knew about it and was complicit; someone did eventually blow the whistle but it brought up the whole issue

of who in the company should be responsible for coming forward and saying something was wrong without fear of dismissal.

We are also of course obliged to abide by the ABPI's Code of Practice (It often surprises me that many doctors and nurses are unaware of its existence) It covers many aspects of advertising of prescription (but not OTC) medicines including such things as sponsorship of meetings. There is a complaints procedure whereby infringements of the code can be referred to the ABPI central office in London who can impose sanctions – not very heavy financially but which can cause considerable embarrassment to the company as there is a case book which is published every month. Most of the complaints come from other companies as they watch each other! There is a lot of time-wasting nit-picking on words in advertising such as the use of superlatives or the definition of a “new” drug, or comparatives – what can be defendably claimed to be “superior to” or “better than” another product. The Code is scrutinised by people in the company for opportunities for commercial advantage, but its real purpose is to restrain marketeers from going too far. It works in practice by insisting that a new piece of advertising (for instance) must be circulated around a number of senior people in the company, including the legal advisor, for comments as to its acceptability or otherwise, and finally passed to two senior signatories which each company must have to carry legal responsibility, one of whom has to be a registered medical practitioner (either me or my deputy) who has been trained in interpretation of the Code, and other a

senior person who is usually a pharmacist or a pharmacologist. There are occasional mistakes – for instance although nothing can be published which has not been through this procedure, a drug rep might write something about his drug for the benefit of local nurses and circulate it just to be helpful but this is not allowed by the Code of Practice and the offender must be severely reprimanded. Then there are the limits imposed on sponsorship. You can be asked to sponsor a meeting at an expensive hotel at Loch Lomond with a gala dinner (you're not allowed to say "gala", by the way – it implies something far too excessive!) and fly all these doctors and nurses in with chauffeur-driven transport from and to the airport, with a coach tour of the Highlands and maybe an hour or two of education fitted in at some time – well – surprise, surprise, you can't do that! But that didn't stop Astra Zeneca who did exactly this a few months ago and were publicly exposed for having breached the code of ethics. The funniest example though is that the ABPI themselves hold a "gala" dinner every year at Grosvenor House in Park Lane with all the glitter and champagne that that implies, and the all the big companies reserve tables and invite their favourite cardiologists or whatever. Then this year one company – I think it was Tokeda - reported themselves to the ABPI for having breached the Code by inviting someone to this dinner!

But to return to an example of the pressures to market drugs in the face of unfavourable clinical data about serious unwanted effects or lack of efficacy: proton pump inhibitors are huge earners and we hoped to do a deal with a small company in Korea who were

developing a new one which seemed to be better than the leading brands made by big companies, and the claims seemed to be supported by excellent Phase 1 trial data etc from well conducted trials. So we subjected it to our own three-armed trial comparing it in a crossover design with both Nexium and placebo and measuring gastric pH – and the data were crap! – sorry, I mean not quite as good as we might have hoped – and the Korean drug didn't perform any better than placebo in subjects in which Nexium worked fine. I had to go over to Korea to explain the situation and I had every senior executive from my company on my back demanding an explanation and suggesting there was something wrong with our trial. There turned out to be a simple explanation: H. Pylori colonisation enhances the effect of PPI's by about 30%; about 90% of the Korean population have H. Pylori, but they hadn't tested for this. We had tested our subjects and none did. So we had to kill the deal but the pressures to find a way out were enormous as this is a multi-million buck market.

So when I am subjected to these pressures within the company I ask three questions: first, are you wanting to act in the same way as you would expect others to act? If you were to put this question to an independent group of experts with no financial interests how would you expect them to react? And finally, if something went wrong and the Sunday Times or the News of the World or the BBC got hold of the story, how happy would you be to give an interview and defend your actions?

I quite often see reps promoting a new drug which performs well against

placebo but when I ask what evidence there is to suggest that it is any better than existing drugs in its class they don't seem to have the information.

Yes – companies in general tend to shy away from active head-to-head comparisons, unless they are absolutely sure that their product is superior, because of the risk that your drug may be inferior, or no better but more expensive, than the other. If you are trying to prove that your drug is better a lot depends on trial design and asking what else can we measure such as pharmacokinetics and quality of life. In the case of analgesics where the placebo effect is so powerful it has been suggested that we stop doing placebo - controlled trials because they don't tell you anything; but there is still great reluctance to do active studies. It takes a lot of courage to stand up in front of the board and say your prize new drug is no better than a generic one. A clinician might still want to try it but you might be shown the door as you have just ruined their market.

The recent case of Gabapentin and Pregabalin is very relevant: Pfizer shot themselves in the foot because they didn't compare Pregabalin with their own gold standard, Gabapentin, presumably because they didn't want to affect sales of the latter. But NHS hospitals have been getting wise to this

and didn't want to foot extras bills and demanded evidence that Pregabalin was better before they would let us prescribe it – I had to present an in-house trial before my hospital would put it on their formulary and GP's still aren't able to prescribe it.

One of the challenges of comparative trials is getting the dose of your drug and the one you are comparing it with right; if you move these by a factor you can substantially shift your results one way or the other, and if you see a clear difference you have look very carefully to be sure you have the right doses.

Do you have to provide comparative data to get a licence?

You have to provide whatever data you've gleaned. Things are moving towards the system in the USA where the FDA are very keen on having a dialogue with a company developing a new drug early on in the process, to discuss what studies and study designs are being proposed. There are no binding agreements at this stage (they are not saying : if you do this and this..... you will definitely get a licence) but they may identify omissions that might give rise to difficulties at the licensing stage. The NHRA here have recently started to do this sort of thing which can be very helpful. They will tend to ask for comparative studies.

Bundling with big pharma

Dr Willy Notcutt, Consultant in pain management, Great Yarmouth

“Bundling” is an old practice of two young lovers sharing a bed without undressing, allowing them to indulge in

a little dalliance and pillow-talk without doing anything they shouldn't. It dates back to the middle ages when a piece

of wood was put down the middle of the bed in the expectation that they would each stay on their own side although there was always the possibility of an eager bedfellow leaping across the divide. Another popular technique in America was to sew one of the parties into a “bundling bag”. Sometimes a little more licence such as above-the-waist nudity was allowed, but at others not only were they sewn up to the neck in a bag but their hands were tied behind their backs as well.

My objective this morning is to talk about my experience and some of the pitfalls of working alongside (I hope) a particular pharmaceutical company (GDW pharmaceuticals, who produce medicinal cannabis), and to pluck out things which raised ethical concerns. (I have extrapolated a bit from experience with other companies to illustrate particular issues)

But first a little background. Cannabis was banned as a prescribable drug in 1971 and made a Schedule 1 drug, which meant it could only be used in research and the odd studies that were done were very limited in their format. Between 1978 and 1991 it was discovered that our bodies have an endocannabinoid system, so just as with endorphins and opioid receptors there are endogenous cannabinoids and cannabinoid receptors which are in fact far more widespread, not only in the nervous system, than opioid ones. This system is involved in sleep, feeding, muscular relaxation, pain and a whole range of activities which are still being explored.

In the 1990’s there was a change in attitude to cannabis. From my

perspective I found that I had a lot of patients to whom I had nothing left to offer. I started reading about cannabis and discovered that it had been a prescribable drug when I qualified. I started looking at the synthetic cannabinoid Nabilone, but patients kept coming back and saying “well it’s OK ... but I actually find the real stuff much better”. I stuck my head above the parapet and became a bit vocal in the press, and was adopted by the BMA as an expert, which I came to regret. In 1998 GDW Pharmaceuticals was set up to look into the possibility of producing a cannabis medicine from plant cannabis and we started clinical studies in 2000 – the first ever, and the project has expanded widely since then. The first product was Sativex (from Cannabis Sativa); it recently became prescribable in Canada, somewhat to my chagrin because we still can’t prescribe it in the UK.

So here I was, advocating the clinical use of a Schedule 1 drug, widely regarded as a drug of addiction, so I had to get my basics right. Like morphine and aspirin it has a very long history but is more difficult to use than these and purely as an analgesic is much inferior. It had drifted into the background partly for “political” reasons but also because it is difficult to produce in a standardised form. It was eliminated in 1971 by the WHO who decided that it was a drug of addiction (and incidentally tried to get rid of heroin at the same time). Curiously the paperwork about that at the Dept of Health has disappeared. It was recognised as a sedative and hypnotic but much better agents for this purpose, viz. the benzodiazepines were being developed and there has been some speculation

as to whether there had been some involvement of the pharmaceutical companies in getting rid of a competitor. There remained however a lot of anecdotal evidence from patients that it could be helpful in a number of conditions; and as basic science started to get things right people started to come out of the closet and say “yes I smoke it and it helps me” and the Multiple Sclerosis lobby came on board after about six years’ opposition.

In the last ten years, apart from Gabapentin there has been no wholly new agent for the treatment of pain – there may have been improvements in delivery systems for opiates and so on, but nothing really new. I felt therefore that if there was any possibility of cannabis being useful we had an obligation to explore it, and that this over-rode considerations of addiction – after all the addictive potential of morphine, for instance, is much greater. So we had to really look at it or finally throw it out. I had to formulate a set of rules when talking about it. Was I to get into the issue of its recreational use or get this separated? The recreational use of heroin is never mentioned in discussions about its medicinal use, and seems to be accepted as an entirely separate issue, and I decided to do the same with cannabis. I will indeed never talk in public about its recreational use. I also resolved never to give an opinion in public about its legalisation.

It’s important to know what “drivers” there are for the development of a new drug. What’s in it for the pharmaceutical companies? There is the entrepreneurial element: we have something new, an exciting new product

that we can go forward with which is going to be good for the company; and that energizes people and is good for everyone. But underlying this are thoughts of the shareholders and a profit still has to be turned. And what are the drivers that get the doctor involved? First of course there is intellectual curiosity, and then altruism – I want to do the best for my patients and I’m on a mission to help them. What about fame? – this may be difficult to avoid, however one might try to shun it. And there are considerable opportunities to make money: some doctors have managed to bolster their incomes very considerably by getting involved with pharmaceutical companies, and even if you only get money for travelling and meals and so on, we have to face the fact that anyone getting involved with drug research and promotion from our side of the fence is exposed to the risk of getting their hands dirty.

And then there is the media. It can be useful but I have had problems trying to control that as the media is a huge two-edged sword. I have made my mistakes like being very rude to a radio interviewer, and in an interview with the New Scientist I described some patient’s lives as crap which even in quotes looks terrible in the first paragraph of an article. I have been into bear pits: I once went on Kilroy and opened my big mouth but the only consolation is that I am still in a job! When Sativex was nearing getting a licence it was decided that I should be “fireproofed” and sent for a day’s training with ex-TV interviewers where I was taught how to answer difficult questions by completely avoiding the issue.

Because I have worked with GDW I have a relationship with their PR manager and it is difficult to be sure if this is a symbiotic relationship: both of us benefit, me trying to be independent, him with a commercial concern; or is it parasitic: me trying to parasitize him or vice versa – is he trying to “infect” me with company thinking? I get on with him very well but I sometimes get to thinking – who’s the glove puppet? – whose hand is where, so to speak!

I’ve also had to deal with politics and have had three meetings with ministers and other MP’s. Other pain experts including Professor Pat Wall were involved in these but at first we got nowhere. Then Dr Geoffrey Clyde suggested a way through and worked with the Department to show them how difficulties could be got round. A meeting with the Minister was finally arranged and it was agreed that I would go with Dr Clyde as the drug company didn’t want to be involved and I had to decide: was I their tame puppy or was I acting as my own man? I was pre-briefed by GDW with “information I might want to use” but we were tip-toeing around the issue of how independent I really was. In the event nothing came of the meeting but I still had misgivings about my role.

Another issue which arose was that of intellectual rights and in a way we sold these out. We did our own independent study design. I was very unhappy about being pushed to do double-blinded placebo-controlled trials but I felt we couldn’t possibly do this with a drug we knew so little about in terms of dosage etc, and it was agreed that we would do n-of-1 studies. We spent about a year

trying to get this through our ethics committee and to get them to see that this was the only way forward. But as the study evolved, although we were trying to be independent the company had to supply the drug and there was a two-way flow of information, and we had to be subject to their audit. For this we had to allow them open access to all our data in the recognition that there would be huge commercial value to them when our study was published. Then we ran out of money and could not continue to be financially independent. We also shared our information and experiences with a small circle of other researchers but they were also all dependent on GDW. So there were many breaches in the wall between us and we could perhaps be accused of working for the company.

And what about the patients? These were desperate people and desperate patients produce two issues: the first is that of their vulnerability, which makes them all too easy cannon-fodder for your study. The other is bias; you treat them nicely and they are very keen to please you. Now we are embarking on controlled studies the problem of patient selection has also arisen: we had to bin a large part of one patient group because they weren’t suitably healthy. Since a lot of medication is going to be used on patients outside the required parameters of age, health etc this raises problems which affect many other studies as well as ours. At a recent conference I met the research nurse working with a particular pain clinic and was horrified to learn that she was ringing people on the waiting list and saying “you will be waiting for at least three months till your appointment – would you like to be seen earlier to be

on a clinical trial of a new drug?!! – and of course they had very good recruitment! Then there is the question of drug companies using patients for publicity purposes or media interviews. I have been asked to find patients willing to do this; they have been anonymized, there has not been any pressure put upon them and no money has changed hands. But there are potential dangers and I have been careful to protect patients from unscrupulous companies

Another ethical issue came up at an investigator's meeting when I was doing a presentation on our methods and experiences and I mentioned that one of the questions we asked patients was "who else is at home?", because the stuff is stored in the fridge and if for instance you had two seventeen year olds at home there may be temptations for them. I was rounded on by two people who thought it was quite wrong of me to be asking this. But diversion does happen, with opiates of course as well as cannabis, and we have a duty to ask appropriate questions. There are devices which prevent the use of a spray until a code is keyed in.

As I have gone along – and I've been in this for five years now and have accumulated a lot of experience and have given a lot of advice I have been aware that at times my brain has been plundered at other times it has been plundered and I have not been aware. I have done some advisory board work for Bayer (who are associated with GDW) and have taken consultancy fees although I have tried to limit this. I have been taken to conferences and put up at expensive hotels, and flown club class; I have tried to keep the time I

spend to a minimum and to keep expense under control but we have to think about these things. I could have become an employee of the company but have preferred to carry on with my NHS work. I have not bought shares in the company but a lot of my friends have plundered me for information and I hope I haven't given any insider information which isn't in the public domain (in any case at the moment the share price is rather low!) One is usually asked at conferences, particularly in North America what is one's financial interest in the company. My employer (I am a full-time NHS employee) is aware of all these activities and all my travelling etc is done outside my normal paid NHS time.

The issue of cannabis-induced psychosis has emerged in the last few months, and was the subject of a very well-balanced Panorama programme recently. It is of course a matter of considerable concern to me; I haven't yet read all the literature but my impression is that if young teenagers are smoking say a joint a day for several years they may develop psychiatric abnormalities as the young brain seems particularly vulnerable. Interestingly the BMA who produced screaming headlines about this didn't highlight another study which showed that the children of recent migrants showed an increased incidence of psychosis. We have only been able to identify three cases of psychosis among 1100 patients on cannabis and in all three this was attributed to a severe urinary tract infection.

There is a myth which has been propagated by the press that Sativex

has been stripped of all its psychoactive properties. Interestingly no-one has tried to correct this impression. There has been one probable suicide among our patients who was video'd by his partner as he was dying. It transpired that he had taken a lethal dose of amitriptyline. We then had the problem of how to handle this and had to talk to the PR man about this. We also learnt that he had had several suicide attempts in the past.

We finally published the paper in Anaesthesia. We were upfront in acknowledging that we had received resources from GDW. The company wanted to see the paper before it was submitted but made no comment, and we had made it clear that we would not have revised it even if they had. I have however seen other multicentre trials run by the company which seem to have taken a very long time to be published perhaps because the results have been rather equivocal. (probably because of the trial design).

.Some concluding thoughts. Cannabis still can't be prescribed here, although it can in Canada. There is a move to ramp up the anger in the press and so on – should I get involved? There are also suggestions of importing the drug from Canada. I can obtain it for my patients but am I a pawn in GDW's hands? Something which will soon come up: should we be advising the Area Therapeutic Advisory Group to buy this medicine when it does come on the market? How should we guide GP's with regard to prescribing it? Am I entirely independent? The reality is that only Big Pharma have the resources to research and develop new drugs. Research is extremely costly. The

bureaucracy alone is a huge barrier to doing research: just to register a project involves filling in a 64-page electronic document which takes about a week to complete. But big pharma needs knowledgeable consultants to advise, undertake research and educate other doctors in the use of their drugs. So we have to get into bed with them. It has become difficult to get totally independent opinions from experts and when journals are looking for someone to write a leading article or review on some topic they can find it impossible to find anyone who has absolutely no connection whatever with any drug company. This is also a problem with people working for the CSM and other regulatory bodies. But I have to ask myself if the fact that I am independent is of use to GDW?

Finally, has my bundling with big pharma been effective? Yes we have cuddled, kissed..... yes, even petted a bit.... *(voice from back of audience – stop, Willy – stop!!)*

Do you regard diversion as your problem? Isn't this more the commercial and regulatory aspect whereas your business is deciding does this thing work?

I do feel that it is my responsibility as a prescriber, with opiates as well as cannabis, but I don't think it matters very much as the amounts diverted are a drop in the ocean compared with what is available on the street. And it's probably better to be injecting clean diamorphine than the alternatives. But I do think we have to be responsible.

I agree but in this context are you doing a research study or acting as a prescriber?

I am trying to look at whether this thing works in a much wider context than the wretched RCT trials.

But if there are teenagers at home are you going to refuse to prescribe it?

No – but I'm going to be realistic about it when I talk to patients and make them aware; keep it locked up and don't broadcast the fact that you are on it.

Can you clarify: are GDW supplying it to Canada?

Yes – they have the world licence on it – for 25 years as the licence is on the plants which can be much longer than on the drug. There is a company which will import it back from Canada and we can use it legitimately as you can use imported off-licence drugs in the UK now – as we have done with lignocaine patches.

Can we all do this?

Potentially yes, when we've got the system sorted out.

The therapeutic relationship

Dr Diana Brighouse, Pain Management Consultant and Psychotherapist ,
Southampton

It struck me yesterday listening to Ian's talk that a lot of it was about processing people efficiently through the system – the words efficiency and rationing kind of go hand in hand. What I am going to talk about is the antithesis of efficiency and even of evidence-based medicine. People who come to a conference like this are marked out from our colleagues in that we all believe in a wider, holistic approach and the philosophy and ethics of what we are doing. I think I can say that everyone here has demonstrated by their presence that they do actually believe in the therapeutic relationship and are committed to it.

I don't actually concede that medicine had been usurped by computers, Cochrane and NICE but it does sometimes feel like it. Let me take you back to the time of your grandparents and the relationship they had with their family doctor. He knew them, their parents and their children, they always saw him and trusted him, and had a pretty good therapeutic relationship with him. I don't know if any of you have tried to make an appointment to see your GP lately; you can no longer make one to see him next week as they can only book within 48 hours, and you have to ring before 8 o'clock, which may be very difficult for some one with pain and disability. You may not get to see your own GP and you will only get five minutes or ten if you're lucky. You may get referred to someone else - say a pain clinic, and in ours you first see a triage team of doctor, nurse and physio for twenty minutes each; they make a

decision about where you go and you may never see them again. You may be sent to the doctor in the pain clinic proper, or the psychologist, or you may be sent for physio, TENS or relaxation or whatever, and see a different person in each of these clinics and with the exception of psychology, quite possibly only once. You may be discussed in a multidisciplinary team meeting where everyone is there except you and then someone will tell you what is going to happen to you. I'm not knocking this system as it is at least efficient, but there doesn't seem to be much of a therapeutic relationship involved. And it doesn't help patients who are at the end of the line. Here I think our practices are quite widely disparate, and I do realise that there are wide differences in the types of patient and complaints we see, and that it is possible that what I have to say may or may not be relevant to your practice.

We are designed as human beings to live in relationship. We define our sense of self in relationship to others. A newborn baby does this with his mother: at first as he sees only the breast he feels himself to be part of his mother. Then there is the beginning of separation as he realises that the breast comes and goes and is part of his mother. There is now incredibly powerful neuropsychological work coming from people like Alan Shaw in the US showing that if you don't have a really good bond forming between mother and baby then you actually develop structural deficiencies in the brain: parts

of it do not develop properly and this can be demonstrated by scanning techniques. The best-known example of this is the case of the Rumanian orphans. These were separated at birth from their parents and cared for in orphanages; well looked after and fed and so on but never cuddled or given any affection because there were so many of them for the nurses to cope with. They were followed up and it was found that large parts of their brains had not developed and they had all sorts of developmental, relationship and mental health problems. And it is the realisation of the disastrous effect of failure of relationship that underpins the psychotherapeutic idea that relationship itself can be healing.

To diverge for a moment: I need to explain why I decided several years ago to train as a psychotherapist. There are two sorts of psychotherapies, first behavioural therapies such as CBT, which we are more familiar with in the context of pain management, and secondly what I would loosely call Freudian therapies. Practitioners of the latter undergo a five-year training which involves personal psychotherapy for this whole period, and I have undergone this three times a week. The point of this is that you have to get to know yourself as you are the primary tool. It is the relationship which you form with your patient which is reparative and healing. That relationship changes you both and you have to be very aware of your own issues, your own strengths and weaknesses and vulnerabilities. I've just come across a quote in an article in the Scargill newsletter which I think is to do with bringing people to God but seems very apposite; it says: "Do not try to call people back to where they were

or to where you are, beautiful as that place may seem to you. You must have the courage to go with them to a place that neither of you have been to before". I think that is a very good summary of what psychodynamic psychotherapy is all about.

There is a problem with all of that *measurement*. That nasty word that came up quite a lot yesterday. Can you measure a therapeutic relationship? You can't do a VAS or a smiley face score; you can do some surrogate measurements such as QUALY's: there are several scores designed for psychotherapy including a particular one used in the NHS called CORE (Clinical Outcome Research Evaluation). But it is very much a surrogate, as if we are saying that the relationship is going to change me and you, what are we going to measure? We can't do a double-blind trial or standardise the patients. Of course the managers hate this because they only want outcome measures and evidence based therapy. There is evidence for the benefits of psychotherapy but it's not readily measurable numerically and we can only use surrogate measures.

I got into psychotherapy about six years ago at about the time that I went full time into pain management because there were these patients who were at the end of the line and I felt that I could offer them something – somebody had to offer them something. So I thought I had better try and do something to improve my counselling skills and went off and did a year's course on counselling in London - and got hooked. I have now completed my training and in a few months' time I shall receive my coveted accreditation with the UKCP.

My colleagues decided that we should cash in on this and use my new skills. We had introduced a triage system, the point of which was to halve the number of patients coming into the pain clinic, because that's all we could cope with as the PCT'S wouldn't fund our expansion. Since doing that we have ruled out a whole lot of patients; firstly GP's can't refer patients until they have tried Amitriptyline, simple analgesics. NSAIDS and physiotherapy; until then they can't even get to see the triage team. Then the ones that can be managed with TNS or physio or pain management or whatever are ruled out, so the patients that reach us are often the ones that you might consider at the end of the line already! Some are amenable to multidisciplinary approach and some to CBT. CBT is excellent but it's not the answer to everything. Some patients go to the psychologist for individual therapy, but her approach is fairly behavioural. So it was suggested that I would set up a clinic – now two – where I would see four patients for an hour each once a week. This is time-limited to between six months and a year.

To give you an idea of this I want to talk about some of the patients I see. First I am going to read from the referral letter from one of my pain management colleagues about one lady (T): "As a child she was abused by her biological father. Her mother divorced him, and married three times more to a string of at least three brothers, all of whom were violent and abused her. The last was only 4 years older than T. T was married twice and the second husband was also violent towards her, and committed social services fraud and claimed rent in her name; she was sent

to prison for nine months and continues to be responsible for the repayment of £13,000 although she is adamant that she was not involved. She has a teenage daughter by her first marriage and two further children, one of whom is hyperactive, by fathers in the army one of whom turned out to be married to someone else. She lives in a one-bedroom flat. She has no social worker and is reluctant to have one as she is afraid her children will be taken away.

While she was in prison she sustained an injury to her chest wall and developed a localised swelling which has been extensively investigated and scanned. This was seven years ago but she continues to get pain which is incapacitating. She uses a TENS machine and gets some relief from buprenorphine patches. She takes antidepressants and has a consistently high BDI score. She has no suicidal intentions and says if she kills herself "too many other people would be made happy."

I've been working with her for nine months so far; it turns out that the abuse was almost certainly part of some satanic ritual. She lives in terror of the extended family catching up with her. She is constantly plagued by the council and social services. She has never, ever in her life formed any sort of trusting relationship with any single person, including her mother. What I am working towards is a trusting relationship with me where she can begin to value herself as a person.

The second patient who was also referred by a pain colleague and whom I have been seeing for a little over a year, was a world class sailor and a

physiotherapist. She started to develop a very odd neurological illness which has been extensively investigated both locally and at Queen's Square and Oxford, without any cause ever being found for her symptoms. She has weakness in her arms and legs which is progressive and she is now in a wheelchair. She has numbness in her limbs and excruciating pain in the numb areas. She is depressed. We have been working together on her absolute hatred of her disabled self. It has emerged that she had a much better relationship with her father than with her mother and she views her disabled self as her weak feminine self which she hates, and only really identifies with the strong masculine side of her.

Since I have been working with these two patients both have stopped complaining of their pain. One of the conditions we impose is that while patients are working with me towards acceptance of themselves they will not receive ongoing pain therapy. Even though they know this is going to be a lengthy process they really don't seem to have a problem with this: one of them may occasionally mention that her pain is dreadful but this is always a "by the way" when we are talking about some thing else.

The third patient was referred with chronic abdominal pain. The situation is somewhat complicated by the fact that she lives on the edge of the New Forest and on the border between the Southampton, Salisbury and Bournemouth HA's and had been treated in all three hospitals. She had been admitted overnight to one or other approximately once a week with abdominal pain. She was sometimes in-

vestigated and occasionally put on a drip if she was vomiting but usually she was just given Voltarol and discharged the next day. No organic cause had ever been found for her problems. She was discussed with our liaison psychiatrist at our monthly meeting and they suggested that she would be a good person to work with me. There was an issue with possible opiate abuse and it was agreed that the drug and alcohol people would deal with this and I would take on everything else. What has come out with this lady – after two or three sessions, not straight away – and she is quite happily married with two children – is that at the age of nineteen she was raped while on holiday in Ibiza. She never told anyone about this and the next day she came home and slept with her boyfriend and became pregnant. Everyone including the boyfriend thought it was the boyfriend's baby but she was pretty sure that it was the result of the rape. This child was adopted by her sister and she has seen her grow up, with the constant fear that one day questions will be asked about her biological origins. This has been a huge thing and you can imagine the impact this sort of thing which had never been expressed before would have on the expression of pain.

Patient number four has pelvic pain. The story is a bit more straightforward as she was abused both by a violent father and a violent husband.

These are all patients who have been judged unsuitable for short – term CBT. They all have issues and they all fit the DSM-IV criteria for somatisation disorder – if you want to give them a label. These patients do come to our pain clinics but we often fail to identify

their problems because we haven't the scope to do so. The more we devolve them around our teams the less likely we are to pick these things up, and they end up as the heartsink patients we can do nothing for.

I hope my practice does have something to offer, but it has to be asked: is it cost-effective if I only see the same four patients a week for up to 9 months? I am going to suggest that this is really very cheap. If we can keep people off the endless merry-go-round of GP and consultant consultations and investigations with no-one getting anywhere it is really very cost-effective. The managers have given me three years to prove this.

You say that you have virtually no waiting list since you introduced the triage team but it takes you six to twelve months to treat these patients – I don't quite understand how this fits.

We factored this in when we presented these plans to the PCT: prior to this things had got completely out of hand with 750 referrals to two of us and we kept having to close our list. We were able to appoint a third consultant and an associate specialist; they then asked us to work out how many patients we could see so we introduced the triage team and factored in the different ways in which we work and came up with an acceptable figure, and they said fine – we'll work out a way of reducing the numbers coming to you – and they have been behind us all the way, and I am hoping to get funding for yet another clinic.

You must get a lot of referrals – this type of patient is quite common, isn't it?

Yes, but a reasonable number go to see the liaison psychiatrist, with whom we work closely. Many are severely depressed and they are not suitable for psychotherapy until this has been treated. Some are referred to the mental health trust, and some are seen by the clinical psychologist, and after this some opt to go into the Pain Management Programme; they want to move forward rather than looking back – we are honest that this can be a difficult and painful business. But I do see the numbers escalating.

It seems to me that you do have an outcome measure if you can estimate and compare the costs of investigation and treatment in the years preceding and following the psychotherapy.

Yes

Is there an endpoint to this or do you have a therapeutic relationship with these people for the rest of their lives?

One could enter into long-term therapy with these people but it is made clear to them that this is not long-term, and that we have to work towards an ending. The analogy that you would draw is that you have become the mother figure in tie transference; you have enabled them to have more confidence in their sense of self, and to be more independent. You're then going to let them go, like a teenager – you're both going to have some anxiety about this, but they will move on. Some like our lady who was ritually abused will need much longer support, but we are hoping that after a year she will feel strong enough to join a group (one run by a psychotherapist in the local rape crisis

centre – an open-ended long term group).

What effect does this have on you - what support do you have?

I have an excellent supervisor. It is part of the code of practice of the UK Council of Psychotherapy that you have continuing supervision for the whole of your working life – something that all doctors could learn from! I see her once a week and spend time talking about my patients. This is enormously supportive but I still have psychotherapy as well. This is not compulsory but I still find it very helpful.

Particularly around the time of ending the relationship?

Indeed – you do form strong bonds with these people – you do get very fond of and protective towards them and it can be tough.

You said at the beginning of the talk that you my need to go with the patient to somewhere neither of you had been before; you must turn up sometimes in places you'd rather not be? Do you not "steer" patients to some extent?

I'm not sure that you do – it's very much patient-led and you respond and interpret – it's quite different from behavioural therapy in this respect in that it is completely non-didactic – they bring up the stuff and you try to reflect it back to them in a way that takes them away from the bad things and towards the good things.

Would it be over-simplifying to suggest that each of us has within us the potential for self-healing and that it

needs someone trained and sensitive to facilitate that.

Yes, this is very much the underlying ethos.

In the context of yesterday's discussion, do these people have a human right to what you are doing – any less than people with broken legs?

They are certainly very broken people.

It still astonishes me that someone could be admitted three times a week to different hospitals with non-organic abdominal pain without being moved in this direction – but in the NHS this sort of thing happens all the time. As a GP I see heartsink patients who have been defined as those you don't want to take by the hand and move into the unknown but the opportunity arises ... I am already running twenty minutes late and there are seven more patients to see – I shiver with reluctance but this may be my only chance – do I go for this now? – and I see between two and four patients a month where you are going to open a can of worms like this.....

There are times when you know you know that you need to sit down for at least a hour with a patient, but general practice structure nowadays, when the patient can only book an appointment on the same day and only get 10 minutes – and for that matter hospital outpatient systems – militates against it, and what you are offering seems tremendously valuable.

Yes all this emphasis on efficiency and putting people through the system at speed means that no-one has time to stop and listen.....

But the patients who are being streamlined through your triage are not the ones that need your help in this way – hopefully they will be pulled out at the triage stage.

Fair enough – my husband is a surgeon and he says all his patients want to know is when he can repair their hernias – they don't want all this stuff!

The question to be asked is: are we here to run a system or to care for patient? How do we get a balance between the two. There are always going to be patients out at the far end of the distribution curve who need extra help but they are not all that many and they aren't going to swamp the system. I was very interested in what you said about self-healing; I was listening to a speaker a month ago who brought a historical perspective to this. He was describing Asclepian temples. You went to see your physic who would give you healing herbs but along with that would send you on an arduous journey in a very beautiful part of the world. There you would find a beautiful temple where you would be given medicine and you would sleep on the floor of the temple. And that was normal practice – all part of the healing process – and the speaker was making a call for healing no longer to be looked on as an alternative to medicine but to rejoin it.

Absolutely – when people ask me why I have spent five years training as a psychotherapist I reply that I went into medicine because I felt I had a vocation to heal people and now at last I am finding it.

These patients pop up in all sorts of clinics – just because they have pain doesn't necessarily make them our patients ...

I feel that helping them is very much a part of pain medicine – but you no doubt may have a different outlook..... What's even worse is that when I talk to the psychotherapists in mental health they say “thank God you're seeing these people – we turn them away – we don't want to have to deal with people in pain!”

There are so few people working in the grey area between medicine and psychiatry They aren't “psychiatric” - OK they may be somatising according to the DSM criteria but that's hardly evidenced based – and they're not properly ill so I don't want them in my medical clinic – but once you start working with these so-called heartsink patients you get to like them and understand them and stop judging them and that's the art of medicine and not the science. When we find out what makes them tick and can really help them that is healing.....

The only people left in the orthodox system who will help these people is us: the alternative is the Alternative! – who often handle them a hell of a lot better than we do!

It's no accident that psychologists are involved because doctors who were the first on the pain scene said “help!! We can't handle this!” But we could as easily be attached to ENT or orthopaedics or whatever, and in some cases are - because they have the same problems.

These patients can indeed be the most rewarding: if after a year you really feel you are making progress you feel great...

Do you feel that it's an advantage to have two hats on? From a patient's perspective is the fact that you are a "medical" doctor and have these other skills an advantage?

Yes – I think so – I think they feel that because you are one of the pain doctors that they won't have to explain so much – that you'll understand all that.

The common theme of sexual abuse made me wonder: are there any successful male psychotherapists?

Yes, many ; but as far as I know I am the only psychodynamic psychotherapist working exclusively in the field of chronic pain.

Given such limited access to psychotherapy I wonder how the rest of us can benefit from your experience and help our own patients in this category?

I think we could all go a long way in this direction without specific training. We have all learnt how to establish a proper doctor- patient relationship. It is all about giving time and space and listening and making people realise that they are being heard; a lot of them have never been heard.

In Newbury where I live I am also a Samaritan, and patients who have been identified as suicide risks are sent to us while they are waiting for specialist help. We see them face to face at first and agree whether they want future

contact to be on the phone or face to face. It's a pilot which has been running for about 18 months and seems to be working very well. Samaritans come from all walks of life and not many have any medical or nursing background. Our only training is in listening skills and holding people in a safe and confidential place.

There are a number of volunteer agencies.

What are the practicalities of training as a psychotherapist?

It can be done part-time but you have to be committed! It is a five-year course; the foundation year can be condensed into weekends and summer school weeks. Most colleges offer a two year one day a week postgraduate diploma with the option of an MA if you want to do a dissertation. You are then awarded the Diploma in Psychotherapy and Counselling. This however is not a registrable qualification but is what a lot of counsellors have. Then there is a further two years for the advanced diploma which allows you to be registered with the UK Council of Counselling and Psychotherapy. But you also have to notch up 450 hours of supervised training for which you have to find placements and which takes up another two days a week. And then you've got your own therapy – so it's all a huge commitment – and you've got to pay for it.

Is the onus on you to collect the data on cost savings?

Yes!

It has been said that no doctor ever cures anything – all he can do is to provide the environment in which

healing can take place. Is this an overstatement?

Ethics and pain in the drug dependent patient: prescribing drugs of potential misuse in drug misusers

Dr Willy Notcutt

If you get involved in treating pain in addicts you find yourself swimming around in uncharted waters. There are a lot of sharks out there, especially legal ones, and we need a set of ethical principles to guide us in these dangerous seas. Why bother? Apart from pain docs and palliatricians, occasionally GP's, and a few doctors in substance abuse there are very few physicians that regularly sit down and prescribe hard drugs. So if we have a set of ethical guidelines at least we can't be accused of not having thought about it.

There is very little on the IASP website on this and nothing on the BPS's, and in the BPS's booklet on prescribing opioids there is nothing on ethics. Ethics get a mention on the website of the American Academy of Pain Medicine, mainly in the context of End of Life issues, but really only the basic ethics you would expect of any professional, followed by the bland statement of intent to "inform and instruct our patients and the public on what we hold to be ethical practice". The American Pain Society do devote some space to ethics of palliative care, high tech stuff, (which a survey suggested members found most important), undertreatment of pain,

managed care, and disagreements on treatment of pain (a lot of those, incidentally). The American Pain Society has an ethics SIG and they've looked at some challenges ahead, including some issues around drug abuse, e.g. when you're treating a patient with a femoral abscess from mainlining or those with HIV/AIDS (whose neuropathy you wouldn't necessarily be treating with opiates) but on the whole scratching the surface of the subject. A paper by Papagallo on treating chronic pain with opiates which is mainly concerned with non-addicts stresses the importance of psychological evaluation and implies that if there is the slightest doubt about your psychological health - you're out.

I have found a new journal Ethics in Pain Medicine which has lots of papers and editorials on topics such as terminal sedation. The American Pain Society has published the proceedings of some of their deliberations on ethics in pain management but it's only just come out and I haven't been able to get it yet. It occurred to me only last night that this group might get involved in working on a Code of Ethics for the BPS.

We have a number of drugs of potential misuse: besides alcohol, the opiates

and the cannabinoids there are the benzo's, the amphetamine derivatives, and perhaps others, and it may be that more of our patients are abusing prescription drugs than we like to think.

I ask fairly simple ethical questions: am I doing good, what harm am I doing, am I doing the greatest good etc etc, and I want to look at these in terms of patients with dependency problems. Firstly autonomy – what rights do they have? They have the right of choice: if they think heroin or more commonly pethidine injections are the only things that help their pain, they have the right to choose it; but Doctors do have rights and duties too: as with abortion they have the right to refuse but a duty to move the patient on somewhere else if necessary. I looked at my own negativity in this situation; you know, that awful feeling when you know you're failing to make eye contact - you know you're not going to like this guy – what is it in me that's wrong? We all know some of the reasons: pain problem not interesting, addict, missed appointments etc

Other issues: patients getting drugs prescribed by us which are not adulterated; trying to get a balance between a therapeutic effect and what might be a pleasurable effect – should it be 100% the former? Not doing harm, either to the patient or to others and society; dependency; escalation pressures. We have a lot of experience now with long-term use of opiates in non-misusing patients but the hard knowledge isn't there.

I was looking at a paper only the other day which touched on treatment of drug dependent patients and it made the

usual pious conclusion: we need bigger and better random, double-blinded etc etc trials – duh..... I mean what world are they living in? It's a great cop-out.

We also have issues around diversion. Are patients taking drugs off us for retail? There may be "accidental" diversion if people have a lot of drugs in the house that family members could help themselves to.

There is also accidental harm: we have a patient who if not misusing drugs is certainly dependent. She has a chaotic lifestyle, involving various services, and difficulty controlling her drugs. Her son had been removed from the home and placed in a children's home from which he absconded. He came home when she was out and found his mum's MST which she was on a quite large dose of. He took a 100mg tablet which of course didn't work within half an hour so he took another and possibly another – and was found dead the next morning.

There are concerns about increasing use of opiates; our local PCT have expressed concern about our high level of prescribing. We are however sure that if it is leaking into the community it is a tiny fraction of the amount available illegally.

Just and fair allocation of resources is a big problem. These patients do take a large proportion of our time and attention. I was rather pleased to see that the Pain Society's booklet on Spinal Cord Stimulation (a very expensive treatment) doesn't exclude drug dependency but I don't imagine such patients get much of a look in even if they have good indications. Justice and fairness is difficult to

achieve in this group.

I saw again recently the woman I described here two years ago who had moved into the district on 5mg diamorphine i/m bd, who insisted that this was the only drug and route that controlled her pain without nausea etc, and had no other social or other problems. She has negotiated up to tds but otherwise there has been no change, and I fear we will continue to take the path of least resistance. (what if she had been social class 5 and obscenely tattooed and pierced?)

The next patient is a guy who had sustained an injury to his neck many years ago while working on an oil rig with some injury to his cervical cord and consequent neuropathic pain. He was a heavy drinker. He had been through the conventional treatment for neuropathic pain but by the time I saw him was into i/v diamorphine, and insisted that this was the only thing that controlled his pain. He was obtaining supplies from the drug dependency unit, who had referred him. Then he injected some Temazepam into his radial artery by mistake and ended up with a grossly ischaemic hand and lost several fingertips. He now has a withered useless hand which not only has CPRS but prevents him from mainlining his heroin. He had been injecting into his groins but had wrecked both of these and was relying on a friend to inject for him. He had also injected into his femoral artery and although he didn't lose his leg it was cold and I had to do a sympathectomy on him.

I seriously wondered if we should give him an I/V port to help him inject, which would be much easier and safer.

If you put in a port and it gets infected with MRSA and he dies, would you pass the Sunday Times test?

I don't think its an unreasonable thing to do. When I worked in the States there were a number of unscrupulous doctors who would put in a subclavian line for a fee (we called it the "drop in the pocket") and their mates would come round and think they'd have a go and produce pneumothoraces. But done in a proper hospital setting it should be OK. This guy is otherwise going to continue to try to get venous access and damage arteries etc..... so go for the greatest good!

Well, I actually did do it. The port got clagged up twice (after telling him he mustn't inject any thing except heroin the silly bugger put in ground-up Temazepam) and the second time there was nothing more I could do. He then disappeared (this was around 7 or 8 years ago) but I made enquiry lately and discovered that he is still alive and drawing his prescribed heroin.

Another patient in his fifties with severe psoriatic arthritis was started on Diconal by his GP (despite campaigns against it many years ago it is still around and many patients like it , and there is an illegal market for it where it gets ground up and injected I/V) He was stable on 6-8 tablets a day. And then we had a big campaign locally against the drug but he refused to take anything else. For someone who had not worked for years he seemed remarkably well-dressed and drove a nice car; and we had suspicions that he was not using all his Diconal, himself and selling some of

it, although there was no doubt that he needed it and benefited from it.....

We had exactly the same problem: someone who was sent by his GP with the express purpose of getting him off Diconal which had been prescribed for his "failed back" by a now retired colleague. We tried every thing else but only Diconal helped and kept him at work so as his GP's wouldn't prescribe it we gave him a year's prescription which he collects every month from the hospital pharmacy. He doesn't see us or his GP and this has been going on for seven years.

I see patients [in general practice] who want "their" temazepam and I look at their drug scheme and all the other things they are on and notice they have run out five days early and I become hypersuspicious. I try to negotiate and get people off things and some are willing but this is a very common problem and I don't know the answer. As long as trust doesn't break down like when someone does something stupid and criminal like trying to cash the same scrip twice and then you refuse to prescribe that stuff ever again....

One problem they have in the USA is that they can get prescriptions from different sources. We have a big advantage here in the strict GP control of strong opiate prescribing and I think this makes a big difference to our prescribing patterns in the pain control business.

If you suspect that he is selling his drugs, do you have a duty to report him to the police?

Well.....

But you also have a duty to observe patient confidentiality, and to look to the greatest good

We could have a whole session on that!

In Canada the instruction from our regulatory body is that we only have a duty to report those things which legislation says we have a duty such as sexual abuse of a minor. We do not have a statutory duty to enforce whatever is the local law regarding medication.

I think that's the position here.....

I did once ring the MDU in a slightly different situation where a patient told me her husband was threatening to kill her.....

I want to finish with one more case of a lady with a history of drug dependency on methadone with spinal and muscular pain who admits to occasionally smoking cannabis and finds that for an hour or two she feels pleasantly relaxed and can forget her pain, and wants to try medicinal cannabis. Should this be a problem? We are perhaps going to have to negotiate a reduction in her methadone dose with the drug dependency people.

Is that any different from her asking for a benzodiazepine for instance?

Maybe you should just tell her to carry on smoking and agree that if she gets caught you will support her by attesting that it is medically indicated?

A patient came to me recently who was on dihydrocodeine -, and he still has back pain - who asked to be referred to

the drug dependency people for his “addiction” He is on a dose he could easily be on for pain.....

So to conclude: we’ve wrestled with the opiates and now we have a new kid on the block and we’ve got some thinking to do; and we are going to have to roll out our thinking for the benefit of the public and our colleagues. There are going to be misconceptions, prescribing errors and so on, and the knowledge we have and our thoughts about the ethical issues need to be disseminated. We need to firm up our ideas – but..... “Modern research has shown that there are no answers”

We all recognize drug dependency but what about doctor dependency? I have a real ethical dilemma: young girl, never worked before she saw me (now in her late twenties). Now she has a job as a hospital domestic, very committed, never has a day off sick, never sees her GP. But.... She has brachialgia for which she gets cervical epidurals and I have now done twenty-three cervical epidurals! – over the last 12 years. We’ve tried interspinous ligament saline and it doesn’t work. I’ve started leaving the steroid out and that seems all right. So what do I do? If I stop she can’t work.

Consciousness and the healing of pain: implications of the difference between objective and “pure” unmeasurable consciousness

Father Andy Graydon, hospital chaplain, Mexborough

When I was in training my specialised subject was Spiritual Psychology, and a Jungian approach which I found very powerful. Since my appointment as Hospital chaplain 11 years ago the job has developed in a variety of directions: I now work in mental health, a pain management unit and a Hospice, so it’s a very varied ministry. I spend nearly 85% of my time with staff who are delivering the real care and I hope I can help them to help their patients but I do of course have direct contact with patients myself.

There have been a lot of words over the last few days so I’m not really going to

talk much today – but don’t worry – neither are you. All words come from silence so I want to spend the beginning of this session returning to our roots in silence for a few minutes: not a distracted silence but what I would call a tuned-in silence listening to the depths of our being. You may find that difficult; don’t try to do it – don’t even think about it – just let it happen.....

There’s a story of an old beggar who spend his days sitting in the street getting a few Shekels or whatever from the passers-by until one day a well-to do looking chap stopped and said:

"I've nothing to give you but I just want to ask you one question: what's in that box you're sitting on?"

"I've no idea", replied the beggar. "I've been sitting on it for twenty years but I've never looked inside it."

"Well look", suggested the stranger.

So he looked and lo and behold the box was full of gold bullion.

"Bloody 'ell, said the beggar – I've been sitting on this box for all these years and never looked to see what was inside it – I'm rich!"

In a sense I've nothing to offer you at all; nothing to add to you. You may think: I'm not a beggar, I don't need anything, but in many ways we're all begging for something, whether it's attention, importance, to be noticed; anything sometimes to make something of our lives. But if we look inside ourselves we will find all the riches we need. So I'm not going to give you anything for your heads. You've got far too much in there already – you're very rich people! You remember when Jesus told this very rich young man: sell everything It's harder for a rich man to get into the Kingdom of Heaven I don't think he was talking about material riches. I think he meant richness of content of head; thinking we've got something in here that's important and will make us something and he's saying: get rid of that stuff ... get into the deeper riches, for God's sake. Our heads are so full of stuff and yet we want more! If you think you're going to get more out of this session go now - if you think you might get less,

that's good. I sometimes think we view life as a supermarket trolley. When we are born our mother sticks our name on it and we go round filling it with as much knowledge as possible – a bit of this – a bit of that – and we always need something else – content, content, content. And so we've overloaded ourselves to the point at which we've lost something deeper. Our minds are fantastic tools but instead of using our minds they have come to use us – the slave has become the master. Have you ever stopped thinking? Because if you think you can't the tail is wagging the dog.

[At this point the audience were shown some pictures of apparently meaningless black shapes which only made sense when one concentrated on the spaces between, which wasn't easy!]

This is what I mean by objective consciousness: people are very much tuned in to objective things; all the material, physical experiential, thought processes. Some people never stop thinking because they are object conscious. Some people are never comfortable with silence - nothing *happening* – they have to put noise on the minute they wake up in the morning; they have to have something objective to work with and feel with. For some people its purely the material – they live and work for possessions.

But there is a deeper dimension which comes from the same source I call space consciousness which is just as important if not more so. I am not saying we shouldn't have the other but if we have space consciousness then the objective sort will make more sense

to us. With each breath we breath in and out 10^{22} atoms. If you were to take an atom and blow it up to the size of Wembley Stadium the nucleus would be the size of a football and the electrons the size of a pea. The rest would be absolutely nothing – not just empty space – just nothing. We are 99% nothing , so how do we make something with that 1%? It's amazing. And we keep exchanging atoms with everybody and everything – we've even got African atoms in there! So we are all interconnected. What we can make of the 1% is very important but it's very limited. I've no great certificates or degrees or titles; the world can make a lot of those but forget the spaciousness within us wherein consciousness lies.

So we need gaps in our lives to give us space to explore this consciousness. The difficulty comes with the belief that without our minds we are nothing, that thought has to take over everything. This last century has been the most destructive the human world had ever experienced. Technological advances have been immense, but we have used our minds to be destructive. The number of humans killed by other humans in the last hundred years has been greater than in all the previous centuries put together. But what gives me great hope is people like yourselves who are a bit more open to the idea that there is more to life than thinking mind stuff, and that there is an intelligence which is deeper than thinking which we call it consciousness. Each of us has a form of consciousness which is expressed in our individualities. Every thing is an expression of consciousness - all life, animals, trees, this beautiful scenery. But they don't think; they're OK as they are. Trees don't want to compete with

one another. My dog doesn't have thoughts – well if he does they aren't any good! - he doesn't get into self-image. But we get so wrapped up in self-image and self-esteem. You all see patients who have suffered pain for years and they are stuck with the mental image of who they are – it's nobody's fault, it just happens.

When I have a day off I usually go off somewhere and sometimes I go to Columba Park in Worksop and I just sit and watch people. Watching animals tells you a lot about life. On one occasion there was this guy feeding the ducks with bits of bread and some teenage kids came along on bicycles wearing tee-shirts for some wildlife association and said: excuse me, Sir, but don't you know that feeding the ducks bread is bad for them – it bulks them up so they don't get enough proper nutrition..... he replied irritably: I know, I know – I'm not stupid. As if he knew it wasn't right. After a few more polite words to which he responded rather aggressively the kids rode off and he walked round to the other side of the pond and started throwing bread again. His mindset was that he got so much pleasure from feeding the ducks that he would keep on doing it even if it did them harm. So many people come along to a pain clinic and they've got stuck in a mindset which may never change.

The key for me is to realise that we need space consciousness in our lives. Many people are not ready to stop thinking even for a little while because the mind will kick in and say “come on – you're wasting your time here – do something more constructive - - do those things which you should be doing”

so we get anxious and get on with something.

We've been here nearly 40 minutes but at every moment we have been living in the present – in fact that's the only place we can live. And what's important about the present moment is not what's happening in it but being alive to it. Past and future are mind things: the mind is great at working out the past and planning the future but it can't cope with the present so it will do anything to avoid having to do that unless you are tuned in to a deeper sense of consciousness. If you are, you find your mind will work better, that there is a better sense of balance in your life, and a peacefulness.

There's a book called "a Course in Miracles" which is very heavy going, but one of the questions it asks is: what is your purpose in life? – and suggests that whatever else is going on your purpose is to find peace and to turn any conflict into peace. Every worry we have is about the future – even if it's about something that happened in the past the worry is about the future consequences. We can't change the future, but if we can live more fully in the present we will have the energy, the understanding and the deeper perspective to cope with it better. And it's the same with the past – if you carry all the stuff from the past around with you it will just weigh you down.

There are all sorts of ways of bringing yourself into the present such as meditation: breathing meditation puts you in touch with your own bodies. But you have to let go of your own mindset, When Jesus said: you must hate your mother, father even yourself I think

what he meant was the mindsets that go with them (my mother would never have let me do that" – would my father approve ?) and let them run your life – Jesus says: get rid of them – learn to be yourself. When he told us to live life to the full he didn't just mean content, he meant life itself, which can only be lived in the present moment.

Can I recommend a book I have found immensely helpful called Stillness Speaks by Eckhart Tolle, who also wrote The Power of Now.

I have a problem with all this: I may sense , I may sit in nothingness to some extent , but how does that effect my relationship with other people? Is our purpose to be individually peaceful and sod the rest of them?

I think we're all interconnected, although your expression consciousness may be different from the person next to you.....

That's just my point: I think one of our purposes in life is to share our consciousness with other people, but how does that fit with individual, isolated meditation?

I would never say isolated. There is a mentality of separation and individuality but it really doesn't exist. Nothing separates us except our minds As soon as we are given a name and experience separation from our mother we become separate in our minds but that's a falsity. Any image we have of ourselves will always be false. Any attempt to defend our image must be false because the real self doesn't need defending. The true self has no image.

OK..... *but what practical use is that?*

To live life more fully.

Who says, and is that right; I'm being deliberately challenging here – how is that going to stop wars pain.....

All I can say is that the proof is in the pudding – I've tried it myself and so have other people.

This brings me back to my point: one of our functions is to share our experience

of battle lines – I'm right, you're wrong.

If I reflect on how I feel in the company of some one who has learnt to live in stillness - it's a nice, calm, therapeutic feeling. If in your endeavours to explore these things you can be more like that and you can give other people a sense of sharing.

When people like Jesus and Buddha spoke they did so from inner consciousness and people got healed. I think if people like yourselves can do so, healing can take place.

I sometimes go to a Buddhist monastery and sometimes I have a chat with myself and the intellectual me asks – what are these people doing – what is with this place? - and I think one answer is that even if all this monastery and it's community is doing is acting as a force for holding the space and contributing as little action as possible, that in itself is a reason for being, but

nothing matters – not in a nihilistic way Every now and again I get an inspired – but everything you think matters doesn't and what you are left with is nothing, and that's what really matters.

– I don't know what your experience is but I believe you – I don't mean that in any patronising sense

Mindsets can put you beyond the reach of sharing. When antibiotics were first introduced the mindsets of many of the practitioners of the time put them beyond the reach of this innovation – we've never done it this way before. Isn't it mindsets that put people on opposite sides

my experience is that it is much more still.

Can I give you a clinical example of a situation where doing nothing was better than trying to do too much, which we physio's are very prone to. The OT and I were working with a profoundly autistic child trying to get him to interact and talk. Previously people had found that the more they worked with him the more he retreated. So we decided to do as little as possible. The only things in the room were the child, a huge physiotherapy ball, and the OT and me. We decided to ignore all the other clinical demands of the day, and simply wait in silence. Eventually he lay across the ball and allowed me to hold it and move it gently back and forth. Nothing else happened for a long time but there was such a sense of peace. Then he spoke – it wasn't really a word so much as a pleasure sound, but it was the first anyone had ever heard from him. That

was one of the most moving moments I have ever experienced in my whole career. And he began to move on from there; just because Ann and I, unlike

the other educators, were content with silence, and to stop thinking and worrying about the time and so on.

Sanctioning sickness and encouraging long term disability; what are our responsibilities? – the pros and cons of signing off sick.

Mrs Yvonne Lode, Clinical Nurse Specialist, the Shaw Trust, Neath

We have been looking at pain services and pain relief in different countries and it seemed appropriate to discuss the Welsh Valleys as an "area of deprivation". It is an area of high unemployment and high levels of sickness and disability. My background is in pain management and rehabilitation. Over the last 2 1/2 years I have worked for the Shaw Trust in Neath helping people with chronic health problems (mainly back and neck pain, musculoskeletal pain syndromes) rehabilitate back into work. We also have a work retention programme to help people with pain and disability to stay in work.

From Minha's talk we heard that, in Nigeria, there is a higher incidence of mechanical back pain in urban workers than in rural workers who do a more physical job. However, we often hear that those with bad backs should give up physical work and sit at a computer or do admin work! We know that mechanical back pain is made worse by being inactive and sitting all day.

The group were asked to consider the questions:

- 1 Are health care professionals sanctioning disability by encouraging people to stay off work with chronic pain problems? Are we also sanctioning passive health care?

[unfortunately the feedback from this question had been lost from the recording – the answer was basically yes to both]

- 2 What are the pros and cons of people being signed off sick/ unfit for work?

Feedback: *There were not many pros except that it was easier for the GP.*

Cons included:

It imposed a role change – and peoples' role and identity is shaped by "what you do" both within society and the family; in the latter setting the role changes from carer and breadwinner to cared for sick person. This and loss of social life at work often leads to guilt

and low mood, and reduced confidence in ability to work.

But what about the long-term sick who have been told: you mustn't work any more, it's not safe for you to work, your job won't be held open, you must go on benefits? Imagine you were a 38-year old breadwinner the head of the family what's that going to do to yourself esteem - almost overnight your role has changed; it's nice not to have to get up in the morning for a few days but then the dread of having nothing useful to do sets in, and minor mental health problems begin to appear, which may develop into major ones; Many people arriving in PMP's have above normal scores on the BDI, sleep problems related to mild depression and stress problems; they may start to somatise the stress and get headaches or IBS and similar problems on top of the pain problem.

So work plays a very important part in defining who we are and there are a lot of implications of being out of work. Some of my current work is with trainee GP's in South Wales I ask them: if a patient comes through the door and says "I can't handle the stress at work - I'm so stressed I can't work", what do you do? Nearly all of them say: I'd sign them off, and when pressed as to any alternatives they might suggest they say they haven't got time, or the skills, and it is clearly easier and quicker to issue a sick note than to listen to patients' problems. I then ask:

what about someone who says they are in agony with their back: and they say; I'd tell them to stay off work and rest for three weeks and sign them off. The Department of Work and Pensions have guidelines for signing people of with

back pain but none of these doctors or their tutors are aware of them. They have so many things to learn they can't be expected to know everything. They seem to feel defeated - why sign people fit for work when there are few jobs for them to go to? GPs do not have the appropriate training in occupational health or in rehabilitation to assess whether people are actually fit to do their job or not, and it has to be asked whether without this they can make sound clinical decisions.

Why in the first place did doctors get involved in writing sick notes?

It's very very rare for a patient to come in who doesn't want to work. I am struggling to help them but then you have the employer - and one of the worst offenders is the NHS - who wants to get rid of them as soon as they know there's a problem, and I have some very angry and frustrated patients.....

There is clearly then a moral dilemma facing us: if we are going to sanction long-term sickness in patients how do we reach the decision that that's the right thing to do? Where does the knowledge come from that allows us to make a sound clinical decision?

What authority do we have to make this assessment?

Absolutely none unless you're occupational health trained!

I have two GP friends who tell me that they don't feel they have the right to refuse to sign sick notes.

They daren't refuse in South Wales otherwise they get their tyres slashed!

The success of my Early Intervention Programme depends on demonstrating that we can get people back to work or keep them there in the first place.

Should one of the outcome measures of PMP's be returning people to work?

It shouldn't be purely up to the patient to find work, especially if their old job hasn't been held open.

But it's still very much up to the employers. Also it is too much a question of being in work or out of work and we need to learn from the Australian.....

If you are working in Occupational Rehabilitation you find that the options for returning people to work are fantastic. We regard a successful outcome as either going back with the same employer, or a different job with the same employer.. to the same job with a different employer, or a different job with a different employer, or you retrain, or you do something called permissive work which allows you to work for a year, retaining the safety net of

your benefit and pension rights, or you do work placements.

There are still major problems with unsympathetic employers

In Southampton the major employer is ESSO. They will allow you to work only for 12- hour shifts – nothing less. They won't consider any part-time, or phased return to work.....

Legally they now have to – I think you're going to see big changes in the next few years....

The Disability Discrimination Act which was supposed to enforce this became law in 1995 – that was ten years ago and where are we??

In sum, we have agreed that we have a moral obligation to rehabilitate people back into work and that employment should be seen as a primary goal of pain management and rehabilitation for those with chronic musculoskeletal pain problems.

Two sisters with Congenital Lamellar Ichthyosis (Harlequin Syndrome)

Ms Margaret Currie, Physiotherapist

We were talking the other night about the way in which a degree enabled one to move sideways into new careers, and

as a physiotherapist who qualified in 1968 I am only qualified to be a physiotherapist. But within physiotherapy there

is an enormous range of specialities to be explored and enjoyed and used in different ways and in which as a person you can develop your own skills and bring in other interests of your own. I had a pretty general and wide-ranging early career and then in 1998 I needed to get a job quickly having been out of fulltime work child-rearing for several years. I applied for a post in Community physiotherapy and was offered one in Learning Disabilities. I wasn't even aware that there was such a speciality, but as I had enjoyed the challenges of working in mental health said I would give it a go, with the condition that if after three months I had decided it did not suit me I would get the community job I had applied for. Fifteen and a half years later I retired from the post! It was such a challenge that it took me through fifteen years of being excited by physiotherapy and along the line learning far more than I ever taught anyone else, and for that I feel very privileged.

Progress in children with learning disabilities is extremely slow; I had been trained to get people in and out of treatment as fast as possible but it doesn't work like that in learning disabilities. We have children coming into our service at three and lose them only when they die, either as children or adults. For us "long-term intervention" means life; even if they are not receiving active treatment they are still on our case-load and there in the background. We might discuss whether this is ethically justifiable. Because progress is so slow everything is approached in a different way. Physio's are accustomed to working in a one-to-one relationship with patients but in learning disabilities one is part of a

huge multidisciplinary team. You have to learn very quickly to communicate and to get them to understand where you are coming from and to listen very carefully to what they have to say. Most of the children in this group have no verbal skills and cannot tell you what they are feeling or what they want so you are sometimes working almost like a vet. You might want to apply the word heartsink to many of them but I have to tell you that I didn't have heartsink children to deal with – I had heartsink parents! Some were very difficult to work with and until I have been retired for seven years I am keeping up my insurance!

I realised when I first started in Learning Disabilities that although I had been very well trained as a physio and had had wide experience in a number of specialities there were huge gaps in my knowledge. Another problem was that although I was being paid by the NHS was working in schools, and social-service-run and private homes. So in not working in a safe NHS environment I was always working where I had been invited. This very much affected both my and my clients' expectations. Another was that there was a massive need for Occupational Therapy, but we had no OT, so I had rapidly to learn to be a physio/OT.

The classical description of Harlequin Syndrome dates back to 1750 when the Rev. Mr. O. Hart described the appearance thus: "the skin was dry and hard, cracked in many places, somewhat resembling the scales of a fish" ('Ichthyosis' is derived from the Greek word for fish). Harlequin Syndrome is the most severe form of ichthyosis. The

condition causes an excessive over-production of skin. The skin at birth gives the child a bizarre appearance and produces a severe shock for parents and staff alike. It is thick, leathery, and yellowed with deep red fissures cracking into the 'harlequin pattern' of plaques.

Other problems may be also be present. The external ear may be small where its growth has been restricted by the plaques. The ears can be covered by plaques at birth. These children may also have deformities of the eyes and lips. In both eversion occurs which prevents proper closing of the eye for blinking or sleep and difficulties in feeding. (Eclabion – everted lips; ectropion – eversion of the eyelids.) The nostrils may be restricted. There is an association with cerebral palsy.

Bands of excessive skin can cause contractures of joints and constriction of circulation in the smaller appendages like the digits.

The condition is extremely rare, with only 100 cases having been recorded by 1981. This has led to debate about the exact nature of the disease. It is believed to be an inherited condition, an autosomal recessive disorder. There is a billion to one chance of any couple having a child with this condition, but then a one in four chance of a subsequent child being affected.

There have been other hypotheses, but the study of these children is made difficult by the small number occurring and by their short survival time. Most Harlequin babies die within the first year of life, from a combination of excessive

fluid loss, heat loss and heat regulation difficulties, feeding difficulties due to eclabion, respiratory difficulties due to keratin in the thoracic wall and secondary cutaneous infections.

If the child is to survive, it is of first and paramount importance that he or she be accepted by their parents and carers. Essential practical measures include effective temperature control, controlled fluid balance and sufficient calorie intake – excessive skin growth requires a high calorie diet.

Emollients are used to maintain skin hydration and prevent excessive fluid loss. In the immediate post-natal phase humidified incubators will help. Immediate post-natal fluid administration and blood sampling needs to be done through an umbilical artery catheter as the leathery skin makes peripheral blood sampling and the use of pulse oximetry impossible.

The excessive skin present at birth needs to be softened and removed. Since 1985 Eretrinate has been used. This drug is a synthetic retinoid derived from vitamin A. How it works is not really understood but retinoids are known to control the differentiation and proliferation of keratinizing and non-keratinizing epithelia. Oral Eretrinate in early infancy is thought to help soften and separate the large plaques of stratum corneum. The drug is potentially very harmful and there is limited knowledge of its long term effects at this time.

Therapy needs to be both aggressive and long term, with daily removal of dead skin, regular use of emollients and antiseptic solution to maintain soft skin

and prevent infections, regular use of liquid paraffin or artificial tears for the eyes and regular external ear clearance to maintain hearing

The prognosis is not known but has improved with aggressive therapy and management. The slowing of skin growth in adulthood may be a beneficial factor. More people surviving with this condition will lead to a better understanding of the pathology and prognosis.

These two girls were born 2½ years apart in 1987/1989. The second child also had cerebral palsy. There was no relevant family history of the skin condition and no consanguinity. Their mother had two other daughters by a previous marriage who do not have the condition. They were both diagnosed at birth and an aggressive medical treatment regime undertaken. Their mother took a very active part in their care from the beginning and continues this today with the support of her husband and family. Their attitude has been one of giving the girls the best possible chance of enjoying their lives and having quality time together as a family.

They presented with very similar appearance and problems. Child 1 was treated for 11 months with Eretrinate. Child 2 was only on the drug for 3 weeks. At that stage she suffered fits. However, she has had no further fits since being 4 weeks old.

Both children had problems with their digits. Child 1's fingers were fused together and child 2's terminal joints had been so restricted by the skin that

necrosis had occurred and she lost all the terminal phalanges of both hands post-natally except for her thumbs. The growth of their feet had also been restricted and some deformities of the toes had occurred. They both had eclabion and ectropion.

Their day has always begun at 4.30am when they are got up and bathed in emulsiderm. They needed to be soaked for at least an hour. Child 1 is then scrubbed all over with a rough flannel to remove excessive skin before being covered with lipobase cream and dressed. Child 2 is soaked for up to three hours and is then scrubbed. Scrubbing is both painful and distressing. Their skin frequently bleeds and itches and they suffer from painful cracking of their hands. They are totally re-creamed and their clothes changed half way through the school day, re-creamed and changed after school, re-creamed at bedtime and again at midnight. Eye drops have to be applied regularly throughout the day to prevent drying of the eye membranes and to protect the cornea. Child 1 was registered partially sighted at age 5. She now needs eye drops every five minutes throughout the day. She also has regular bricanyl for her asthma.

Both girls had early gross motor development delay. Child 1 crawled at 22 months and walked at 23 months. Child 2 was just walking at entry to nursery unit at about four years. She has cerebral palsy with a predominantly hemiplegic pattern and mild learning disabilities. Both girls have had physiotherapy intervention from a early age.

The girls live with their parents. Child 1 attends a main stream school and child 2 a special school. Both children have a classroom assistant to look after their skin care needs while they are at school. Child 2 takes part in all school activities including swimming. She has a physiotherapy programme which is carried out by her parents and carers and is regularly reviewed by the physiotherapist in close liaison with her parents and teaching staff, and includes passive and active stretching to minimise flexion contractures, balance and gait training, breathing exercises and orthotic management.

The lipobase cream which is applied thickly meant that she was difficult to handle physically because she is very slippery! The cream soaks through her clothes and anything that she used becomes coated. With the co-operation of the staff at school she has her regular physiotherapy sessions prior to her lunchtime creaming. If the session is moved from this time her specific carer will re-cream her after treatment. All equipment used needed to be cleaned. Her skin dries out quickly and became red and hot with activity. By the end of each session she needs to have a drink and to be discouraged from scratching.

During the first eighteen months I worked with Child 2 (4 –5 years old) her gross motor development progressed well. Her thoracic mobility and chest expansion improved and subsequently her breathing and exercise tolerance also. Words that had been whispered at first were eventually shouted!

In spite of her finger deformities her manual dexterity is reasonable and functional. Playing with sand, paint, and

textured material all caused problems and discomfort, but with care and imagination the difficulties have been overcome. It is necessary to follow all these activities with a skin care routine, washing, and re-creaming.

Child 2 is able to understand and respond to instructions well. As a young child she was able to distinguish between 'hurt' and 'stretch' and would indicate pain. She is very tolerant of her demanding care programme, enjoys the physiotherapy sessions and worked hard to achieve the aim of each activity.

The lipobase cream causes other practical problems. It soaks through everything including her leather shoes which need to be frequently replaced. She also needs large quantities of clothing which could be 'hot washed'. The family have had problems with washing machines clogging and the seals perishing. Furniture and carpets become coated with the cream.

The care regime makes their day very long but procedures cannot be omitted without adding to the girls' overall discomfort. This has made trips away from home very difficult. Their trip to Euro-Disney in October 1994 needed much planning to ensure that they had all the necessary equipment and had the facilities required to carry out their skin care routine.

It may be asked whether the infliction of so much daily discomfort - the scrubbing alone was painful and distressing - in a child too young to understand why it had to undergo so much suffering - could be justified in view of a prognosis at best uncertain, and the certainty that what the rest of us

would regard as a “normal” existence was never going to be possible. These doubts sometimes assailed both parents and carers. But in spite of all their problems the girls are a joy to know. They are happy, full of fun, and have an obvious love of life. They are much loved by their family and all who meet them.

[Unfortunately the recording failed at this point and the subsequent discussion was lost. Nevertheless the reader's own thoughts will doubtless be provoked by an account at times distressing but ultimately heart-warming]

Note:

Since the conference it was announced in a local TV programme featuring the girls that some sort of pharmacological breakthrough had been achieved which means that aspects of the condition are now treatable. A comprehensive review dated November 2005 mentions among “newer “treatments” : Locobase fatty cream, which is 5% lactic acid and 20% propylene glycol in a lipophilic cream base; topical *N*-acetylcysteine, which has an antiproliferative effect; tazarotene topical 0.05%, a receptor-selective retinoid; and calcipotriol, a synthetic derivative of vitamin D-3, as well as alpha-hydroxy acids and other topical and systemic retinoids. It does not suggest that any of these could be regarded as a breakthrough.

Case presentations: two patients unable to accept the only measures likely to help them.

Dr Paul Martin, SPR in Palliative Care, Dundee

The first was a man of 38 who was financial manager in a firm owned by his father, and both his parents lived in Singapore. He was married to a nurse who as an unstable epileptic wasn't working at the time, and they had a twelve-year old son. He had presented with a painful swelling in his forearm which turned out to be a really complicated osteochondrosarcoma for which he needed an amputation. He didn't have any chemo- or radiotherapy. In 2003 he presented with low back pain and on plain films and MRI he was shown to have a lytic lesion which had destroyed one ilial wing and was destroying three lumbar vertebrae. Pain was a constant feature. Later that year he was found to have pulmonary met's. He received radiotherapy to his spine. Over the next year and a half he was managed with the works: paracetamol,

NSAIDs, tramadol, MST, Gabapentin, amitriptyline, dexamethazone, fentanyl, hydromorphone and even a trial of Nabilone. He and his wife were very interested in complementary medicine: they didn't know a lot about it but were very keen on it, and they were referred to me to try acupuncture, which helped a bit but never took his pain away. As time went on he remained in misery, unable to work. He asked for a referral to the medical oncologists, who brought him in for a trial of a new drug, although there is no proven effective treatment for this type of tumour.

So he was in and out of the hospital and the hospice. His attitude was one of determination; he was going to beat this – he had “things to do with his life” – but when I asked him what those things were he was very woolly about it. The

only thing he mentioned was holidays; his business was ticking over and he had no financial worries. He had a strange and difficult relationship with his wife but a very loving one. Their lives had become totally dominated by pain, the disease and the management of both. In the last year of his life he probably had something like forty consultations with medical and nursing staff. His language was always combative: “winning the fight” – “beating the disease”. Despite the progression of the disease they did manage to go on holiday to Turkey, and he showed me some pictures in which he appeared very happy and relaxed. But when he got home his pain was a huge problem, and I and the pain team were running out of solutions. I did a single-shot epidural with LA and steroid which lasted about ten hours. I then put an epidural catheter in which gave him definite relief for about six hours but when the pain returned we couldn't get relief back. I was getting worn down with this. The pain team came over and resited the catheter and the same thing happened. I was on one weekend and they'd had a terrible night: he'd been screaming in pain about once an hour and had kept the whole hospice awake, and had had no sleep all night. He was worn out and very, very frightened. By this time I had formed a very close relationship with this man. I don't know why – he was just six years younger than me and somehow I felt very close to him. I made some adjustments to his syringe driver and went home. I made myself a cup of tea, sat down and suddenly found myself weeping onto the kitchen table. I had a little insight into my own problems so I phoned a colleague and we agreed that I would withdraw from the situation for a few

days and take an already planned holiday. On my return I found that he had been seen by both Bill Macrae and Dietmar Hartmann from the pain team. They had agreed with the neurosurgeons for the insertion of an intrathecal catheter and pump which worked for just twenty-four hours. One of my colleagues who was caring for him in my absence suggested some sort of sedation which he refused outright. So we were left with this man who was screaming every hour, utterly distressed, and nothing to offer except him the sedation which he refused. We involved a liaison psychiatrist at this stage who took a quite assertive line with him, telling him that he couldn't expect us “play this game” (she actually used those words) of him saying “you've got to control my pain but you can't sedate me” So after consulting with his family he agreed to some sedation – with phenobarbitone - and about a week later he died. He stayed asleep all this time; there was no screaming, not even tachycardia or lachrymation.

The second patient is still alive. He is fifty-two, a builder though unemployed through illness. In 1994 he presented with a painful swelling in his chest which turned out to be a chondrosarcoma. This was resected and afterwards he suffered from de-afferentation pain for which he was being treated by the Pain Service. Nine years later he presented with facial pain and was found to have a 7cm round lesion in his maxillary sinus involving the maxillary and mandibular nerves as well as the cavernous sinus so he was not deemed appropriate for surgery. Radiotherapy did reduce tumour size by about 20%, but he remained in pain for which he was treated

with methadone, amitriptyline and dexamethazone. His appetite was stimulated and he has put on about six stone. At the beginning of this year we were involved because he had cancer – no other reason – as he was still being cared for by the pain team. He developed a new pain: a burning, shooting sensation in the lateral side of both thighs. Meralgia parasthetica was suggested which is associated with obesity – he is huge – but he couldn't lose weight - he snacks on cream cakes. He can't sleep in bed but falls asleep, smoking, in his armchair. He was and remains utterly miserable. He has had a variety of analgesics from us: methadone, ketamine, ketorolac and amitriptyline: we can't get his steroid down without lancinating pain in his face which is worse than that in his legs. We offered him psychological help with learning pain coping strategies but he refused. His relationship with his wife is extremely strained: she is devoted to him but he loses his temper with huge rows on almost a daily basis. He has expressed suicidal intention; he says he would never do it for the sake of his wife but the day is getting closer when he might change his mind.

He was scanned again recently and there is no evidence of tumour progression or spinal metastasis (after thirteen years). I injected his lateral cutaneous nerves with good effect for only six hours, and a single shot caudal lasted for ten hours. I then put a catheter which worked well until he caught it on something and snapped it. He was admitted two weeks ago with a suspected DVT which turned out not to be one, but his legs have become very oedematous and he is now in the infectious diseases unit with cellulitis of

both legs. They phoned me last Friday because he was in severe pain but I declined to go as I am getting lost with this man. His only analgesia at the moment is a fentanyl patch prescribed by his GP.

I seem to be on a journey with him to places I don't want to go to. Most of his problems seem to be basically attributable to his obesity but he can't or won't try to lose weight, and nothing short of drastic measures such as gastric bypass seems to hold any hope of enabling this. He has a long way to go so far as his disease is concerned. We could put in an intrathecal pump but this is a big deal. There has been a suggestion of surgical decompression of his lateral cutaneous nerve but the neurosurgeons say they have never done it and have heard that it doesn't work.

Is this typically a male thing? I mean they are both fighting in their own ways.

He could have a laparoscopic gastric banding.

Does he want to lose weight?

Yes, absolutely and he tries now and again, and loses three pounds in a week but can't sustain it.

If his pain goes below the knee it's not meralgia parasthetica but the block did seem to relieve his pain.....

What I wanted to have the main part of the discussion on was something I got to thinking about, namely the expression of pain. Is pain something that can be relieved by pain killers or can it be something else? I think it can:

in the case of the first patient, here was a terrified man who didn't know what he wanted from life, had very confused relationships etc whose angst was expressed as physical pain, so the treatment of his physical pain didn't work. Pain was a family issue; I met his wife recently and she recounted terrible problems with her son who refuses to accept the situation but won't speak about it or accept counselling. My colleague who eventually persuaded him to accept sedation had pointed out that the situation was affecting everyone – not only his family but also everybody caring for him in the hospice and the other patients. I have become interested in using principles that you see in addiction medicine of acceptance of powerlessness and letting go, but it takes a long time to work through these processes. I did invite the first man to consider accepting that he had a disease from which he was going to die but he refused to accept that.

When he agreed to sedation did he realise that that would be it until the end?

If he did he didn't verbalise it...

Because I wonder if he was given the opportunity to say goodbye to people?

He did – but it was only a couple of weeks before the end that the family accepted or would talk about dying. I think he was terrified of dying, among many other things. There is a phrase I have wanted to try out for a long time: pre-emptive psychosociospiritualcultural analgesia. Might he have benefited from going on a psychotherapeutic journey with someone when his diagnosis was first made? If he had done that, might

his expression of pain been different and more amenable to pharmacological relief?

We have psychologists working in the hospice and this is really helpful; this is offered very early on in the journey and people usually refuse the first time, but it is offered again many times and people find it very helpful.

Do you have a carers group?

Yes but the second patient's wife will only attend as her husband's wife – his attendee, so to speak, and won't talk about or even acknowledge her own problems.

When I talked about accepting powerlessness and letting go I meant both for patient and therapist.

I think if they had been able to take on board the nature of the condition and its probable outcome it would have empowered them.

This works well for addicts – it is how AA works – once you have accepted your powerlessness over the drug you can get on with life. These two men continued to suffer so there must have been a prize in it for them: it could have been something positive like lots of attention but it could also be avoiding fear. Let me go on coming to the clinic and getting medication etc – anything so long as I don't have to think about the fact that I'm going to die.

There are other ways of beating cancer than living for ever

Yes – I have been asking – what is the purpose of care? Most people will say

to enable people to live longer, but then I ask: OK, but what are they going to do with that longer life? If you invite people to talk about prognosis they will say: I want to know – and yet I don't want to know. And I tell them – and it's the truth – that I have no idea how long they will live – well I do have some idea but I can only use the vaguest of terms – but then I ask: if you knew, what would you do? Often they don't know and I say: well think about it and do it, even if it means going off on holiday without insurance.

We have a day centre and amazing things happen there. People have a rather negative image of day centres as places where they sit in a group waiting for someone to say something but ours is very proactive; a lot of creative work, not just art and music but writing and poetry – often things people have never ever thought of doing. Some people learn to read although they may be very reluctant to admit to illiteracy at first. And they go all round the world on holiday – there are insurances available for people in these circumstances.

I must say that this arises almost always in older couples with whom I have a good relationship to whom I can suggest that they have an opportunity; they have been given notice of something that is going to happen to all of us and they have an opportunity to reflect on their relationship and what life has meant to them and so on, as well as doing all these things – but I feel very hesitant to say to a young man in pain: here! - this is an opportunity! – perhaps partly because he is only a little younger than me with a young family and he makes me aware of my own fragility.

People do grow in the last months of life, I have seen...

Is this guy a victim of our death-denying culture?

Yes but he chooses to stay in that role. If you really want to get me going, I would like to see lessons in school on death as a part of life; I get looked at strangely when I say that not all people who are dying are ill. Death is the same as birth in this, and palliative care practitioners have been likened to midwives for the dying – a midwife who acts as a companion in labour is as good as an analgesic, and the same applies.

The screaming you describe as being at night – was this more pain or more suffering at night?

I think mainly suffering; he did describe “spasms” and you could see his legs flex up – we tried clonazepam. It's a very long day in a hospice – you can read, listen to music, go down to the music centre, even go out but for a chap used to running the finances of a big company there are many hours to fill in. And in our part of Scotland, in the summer it is light almost till midnight

Even those people who have accepted their situation will tell you that it is a very lonely journey. We have all experienced the loss of one person, one relationship in life but these people are facing the loss of all relationships - and it is a terrifying prospect.

But also – mainly with older patients – I do have the privilege of working with people with a sense of peace. I remember one old lady who knew she

was dying and wanted it to be in the hospice; when I asked her how she felt about it replied " oh, everything's fine, I've got the funeral organised and I've got him a suit"!

Is it our duty to require a person to address his fears? If you are bringing up a child you would say: you can't do that – that is unacceptable behaviour – is there a similar duty....

I don't think so – but I am avoiding the question by referring to the screaming which was disrupting the hospice and upsetting other people.

- which is unacceptable behaviour, so don't we have a duty to say: you must talk about this, or at least sit in a room with someone, and this is what we require you to do.

This brings up the ethical principle of autonomy – is this always right?

*Your colleague had to be quite as-
sertive to get him to accept sedation.*

That's what I had in mind when I talked about pre-emptive palliative care. It seems to me that in the UK at least palliative care is always reactive. I and a colleague have been looking at the possibility of routinely getting a referral to palliative care at the time of diagnosis, and having parallel consultations with oncologists and surgeons, so if necessary we can start on the psychotherapeutic journey of confronting and dealing with past and present fears.

Our Macmillan nurses are always saying: if only we had been asked to see this patient sooner.....

I don't know how many people are aware of the new "Gold Standard Framework for Palliative Care" which "embodies an approach that centres on the needs of patients and their families and encourages inter-professional Primary Care teams to work together to improve the way these are met with better communication and teamwork within primary care, and better collaboration with hospices and specialists in palliative care". I have been very impressed by the way in which very experienced GP's have sat down to discuss cases for the first time ever. It establishes links with district and Macmillan nurses and with out of hours services which is most important because communications can get very disrupted and night and weekends.

Whatever we do to try to pre-empt these situations there is inevitably always going to be a small number who slip through the net and for whom we run out of options – we can look back and learn lessons but I'm not sure that we can ever eliminate that fraction of 1%....

Yes – and it's our acceptance of that which can be the issue. As the ENT surgeon said of the second patient, you have to apply the principle: don't just do something – stand there! The temptation is to keep trying.....

Summing up

Reverend Walter Currie, retired hospital chaplain

I'm not going to try to go through session by session and pick things out as I don't think that would be helpful. What I do want to do is to tell you what these three days have triggered in me. I feel a little like Charlie Brown when he and his pals were going to have an evening of self-improvement: Linus was to bring something along on the logical positivism of Wittgenstein, Lucy the latest on the rise and fall of feminism in the twentieth century, and Charlie admitted to planning to bring his favourite red bus. So there is nothing very profound in what I am going to say.

Firstly I thought it was very valuable to have, in David, someone from a completely different discipline – if only to make us think. One thing that emerged in Minha's session and later was that when it comes to developing pain management issues it's not just a matter of training in skills but educating in attitudes; changing these takes time and we have to be prepared for that. The history of medicine is full of examples of this. Another thing that emerged was the need for structures which also take time to create – they don't happen overnight. We need patience, vision and wisdom in order to do this.

So far as developing countries are concerned the question at this stage is not so much what can we do or how can we help, so much as finding out what help they want. It was rightly remarked that developing countries may be poor in material resources but rich in spiritual resources, and the opposite

true of developed countries, so any links between them needs to be two way. We have a lot to learn from developing countries which means listening, listening, listening.

And listening is of overwhelming importance in every other context imaginable: listening to your patients, your colleagues, to their relatives and to yourself, and to keep listening. It is perhaps the most important element of being with people, and it is not so much the amount of time you spend on it as the quality of that time; you must be totally focussed on the person to whom you are listening.

Listening to Paul's talk I was reminded of the introduction to the book about the Eden project written by it's creator Tim Schmidt. In it he quotes his grandmother's philosophy: "when I get to the end of my life I want to be able to say 'I'm glad I did' rather than 'I wish I had' ". When you get to a stage of your career, when you retire, when you get to the nursing home – when you get to die – you want to be able to say: I'm glad I did. Do it – go for it!

We do live in a death-denying society. I still have a cutting I took from the local press when a lady in our hospice died. She had been a prominent Christian Scientist, and was well-known in Norwich. After chronicling her life's achievements it concluded by saying that she had died quietly at home – but we had watched her die in Priscilla Baker Lodge – denial not just of illness but of the illness that was terminal.

A long time ago, but never to be forgotten, I met and talked with David Jenkins, the notorious Bishop of Durham. That conversation made me realise how much he had been misrepresented by the media. He was a gracious, caring person with a razor-sharp intellect that worked far more quickly than he could possibly speak. I still remember some words from his address at that conference: “we need to grasp the simplicities to be able to live with the complexities”. He was talking about faith but it applies to so many other fields, doesn't it? – medicine,

philosophy, attitudes to life, relationships. We have been confronted with both simplicities and complexities in the last few days. I don't think we will ever learn to live with the complexities unless we have learnt to live with – and grapple with – the simplicities.

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