

A>MAD

Action on Mind Altering Drugs
Campaign for Medicine Safety

An Open Letter on the Human Tragedy of Benzodiazepines in the UK

5 January 2006

Dear Professor Appleby,

For 25 years since the CRM statement in March 1980, the Department of Health has declined to do anything effective to protect the health and lives of patients who could potentially become addicted to prescribed tranquillisers and hypnotics or who were already addicted to these drugs. No rational explanation has ever been given for the inaction. Emphasis should be placed on the word effective. Guidelines which are by definition advice, can never be seen as an effective protection for patients. In spite of the 45 years of iatrogenic health damage that has occurred in this country, the best that Ministers and civil servants can do, when seeking to avoid answering points made by the benzodiazepine knowledgeable, is make statements which are designed to reassure the uninvolved and ignorant that something effective has been done –

"We regard dependence on benzodiazepines as a very important issue and the Department of Health has taken a number of measures to tackle the problem. The main focus of the Department's action in this area has been to try and prevent addiction from occurring in the first place by warning GPs and other prescribers of the potential side-effects of the prescribed medicines and the dangers of involuntary addiction to benzodiazepines." – Caroline Adams, Political Office, 10 Downing Street, London SW1A 2AA, March 19, 2002.

"...We take the problem seriously." A. Higgitt at DH 2002

"...innovation is being rolled out in waves..." Gul Root at DH 2004

"...treatment is available in primary and secondary settings..." Rosie Winterton DH Minister 2004

In May 2001 you said:

"It is difficult to defend that we have such a huge problem of benzodiazepine prescription and long-term use and therefore dependence."

You referred to the situation as a disaster.

You are well aware, that any examination of the logic of the situation from the point of view of affected patients or the impartial, would conclude that it is **entirely** indefensible. Benzodiazepine addiction causes much ill health and cures nothing. There are still doctors who do not appear to know this and the DH does nothing effective to enlighten or control them. References to the responsibility of PCTs or the ethical responsibility of doctors is not action, they are merely statements. Protection of Health is something quite different.

When you were asked on the BBC's Tranquilliser Trap why nothing had been done to prevent the damage produced by tranquilliser/hypnotics, it is doubtful whether you stopped to consider the full implications of what you were saying when you said that it was difficult to change the prescribing habits of doctors. At the core of that statement is the strange idea that even if the DH is aware of the negative health impact of a drug it has no ability to protect citizens in a healthcare system it maintains and theoretically oversees and which the citizenry finances.

There is also the point that if it is indeed true that doctors are a law unto themselves, then the Guidelines issued by NICE on SSRIs on 6 December 2004, will take a long time to sink into the consciousness of most medics particularly as the NICE website has this to say about Guidelines:

Clinical guidelines are recommendations by NICE on the appropriate treatment and care of people with specific diseases and conditions within the NHS. They are based on the best available evidence. Guidelines help health professionals in their work, but they do not replace their knowledge and skills.

No doubt then, the DH will find itself replying to letters on SSRI damage years later, in the same way it replies to letters on benzodiazepines now. It will refer to the NICE advice, the views of the MHRA, the advice in the BNF, the responsibility of the PCTs to monitor prescribing and to the ethical responsibilities of doctors. And in the meantime the patient will bear full responsibility for side effects for the simple reason that he/she made the mistake of turning up at a surgery in the first place. That patient will not be recognised by the DH, the GMC, the PCT, the MHRA, the legal system, politicians or his doctor.

When you know as I am sure you do, that Professor Malcolm Lader said many years ago now, that benzodiazepines were harder to withdraw from than heroin, and the effects could go on indefinitely, you ought to agree that patients deserve something more than statements which are untrue or mere spin. They should in fact merit real support, which actually does exist. And in the context of reality where medically produced addicts find it impossible to secure help from anyone, it is particularly fazing to see the millions poured into illegal drug addiction support.

The senior Adviser at the DH on benzodiazepines - once a colleague of Professor Lader, said -

"There is no doubt at all that benzodiazepine addiction and its health consequences are an

iatrogenic illness.” Dr Anna. Higgitt 1990:

"PWS (post withdrawal syndrome) is likely to be a genuine iatrogenic complication of long-term benzodiazepine treatment" Higgitt A, 1990

She now appears to use her official position to conduct damage limitation and DH formulated statement production, rather than introduce an effective policy to prevent loss of life and health. Is it not surprising that the benzo-affected doubt the motives of the Department of Health?

From the misnamed Customer service department of the DH come the following gems.

“The Department have no plans to issue central guidance on which forms of benzodiazepine treatment centres are to be provided, and in line with the Department’s policy of Shifting the Balance of Power, decisions about service provision should be taken locally. It is for Primary Care Trusts (PCTs), in conjunction with Strategic Health Authority (SHAs) to plan and develop services according to the needs of their local communities. When commissioning services, PCTs will need to take into account whether it is in line with locally agreed health priorities and that its provision will be a clinical and cost effective use of resources. This does often mean that PCT’s have to make difficult decisions about how their finite resource is spent.”

But what if in the real world these 'service provisions are not made? The Department of Health apparently does not know and apparently believes it has no responsibility to know:

“The Department of Health does not hold details of service provision across the country. Your SHA may be able to advise if they can provide you with further information about the local services available but as with any other condition, access to specialised services is through a GP and that is where people should refer themselves for assessment.”

Perhaps shifting the balance of power should more appropriately be described as an avoidance strategy.

And the final insult in a scenario where SHAs and PCTs do not provide services is the official view that the thousands of medically afflicted should be left to their own limited devices:

“... we do not believe that establishing specialist benzodiazepine dependence treatment services would be a cost effective or efficient use of resources.”

Attempts to inform the Department of Health about the real world of benzodiazepine addiction mystifyingly meet with surreal statements such as the following:

“User and carer involvement is nowhere more important than it is in mental health. Empowering patients to take an active role in their care is a key theme in the Government’s mental health policy. This is why prescribers should inform patients about the treatment proposed, including any possible side-effects of prescribed medicines.”

If patients **had** been empowered and **had** been informed, they and campaigners would not be writing to the Department of Health to report on continuing harm today.

And finally:

“We would like to reassure those with dependence on benzodiazepines (the DH does not like the word addiction I know) that many people access services in and through primary care, including people whose main problem is physical rather than psychological or psychiatric.”

The DH promotes the view that present arrangements draw on a wide expertise regarding benzodiazepine addiction and withdrawal. The Department is consistently at pains too to confine any examination of the tranquilliser question to the psychiatric/psychological field and ignore the very real physical dimension of the addiction. Moreover, the lately President of the Royal College of Psychiatrists, Mike Shooter, said in the BMJ in 2003 that his speciality was **not expert** in the area of prescription drug withdrawal. In 2004 the BMA said that GPs **did not like dealing with addicts and had little knowledge of withdrawal procedures**. I wonder if you appreciate the glaringly obvious contradiction?

And why is it that Professor Heather Ashton, a world expert on benzodiazepines, had this to say to Rosie Winterton when the minister gave the same assurance as the Customer service Unit?

“What are needed are dedicated clinics or other arrangements to help people already dependent on benzodiazepines to withdraw. You state that “treatment is available in primary and/or secondary care settings” for those who have developed dependence on tranquillisers. This is simply not the case. I, and many others in the field, get daily telephone calls/letters/emails from benzodiazepine-dependent people who are desperate because they are receiving no help or advice from their doctors and cannot find any support groups or benzodiazepine withdrawal clinics...”

Take benzodiazepines legally and you become a non-person, take them illegally and you become a much thought about and sought out person. And a wish to avoid pursuing illegal benzodiazepine users with more rigour in case they are further oppressed, is in the view of Professor David Nutt a reason for not reclassifying benzodiazepines as the dangerous drugs patients and informed medics know they are.

On 13 May 2004 Gul Root, Principal Pharmaceutical Officer, Public Health and Community Services, Department of Health, searching for something which could cast a positive light on the inaction of the Department, gave as assurance that something was being done, a reference to the withdrawal clinic that Professor Ashton ran in Newcastle. Unfortunately for addicts that has not operated since her retirement from the NHS quite a few years ago. One wonders why it was mentioned at all, particularly as Professor Ashton is highly critical of DH policy.

Other seemingly worthy initiatives were described:

...We are aware that some PCTs have developed schemes to reduce prescribing of benzodiazepines...

In that respect in a letter to Barry Haslam of Beat the Benzos in November 2005 , Alan Higgins the Oldham Director of Public Health had this to say:

"...Oldham PCT is one of a small number of PCTs to not only take the matter of benzodiazepine addiction seriously but to commit resources towards its reduction..."

So after nearly half a century of benzodiazepine mis-prescribing, half a century of medically-induced ill health and half a century of aborted lives and deaths, a small number of PCTs take the 'problem' of benzodiazepines seriously and the Department of Health maintains the comforting myth that much has been done and is being done - that the responsibility lies with PCTs and SHAs. And the resources Oldham PCT have put into withdrawal? Forty three thousand pounds for a year – enough for one worker. There are 5000+ long-term addicts in that city alone and well over 1 million in the country as a whole.

Other interesting statements were:

...The Department of Health funded Medicine Management Collaborative, which is being rolled out in waves, has demonstrated innovation and good practice in many aspects of medicines management...

...There are currently at least 7 PCTs within the Collaborative programme who have developed schemes to improve benzodiazepine prescribing...When these schemes are fully rolled out across these PCTs there is the potential for over 27 million of the population to be getting help to make better use of their medicines....

*There are **302** PCTs in the country.*

If the Department of Health and its drugs regulators had acted years ago in a fashion befitting their stated aims i.e. the safeguarding of public health, instead of preferring to maintain the myth of clinical judgement and the economic vibrancy of pharmaceutical companies, patients would have been able then to make 'better use of their medicines'. But this is not an issue of patients making better use of medicine, this is an issue of a government department playing with words for 25 years, spinning around the huge damage uninformed doctors had inflicted and still are inflicting with tranquilliser and hypnotic prescriptions.

...An addiction therapist who works across the two Wakefield PCTs helps and supports patients, especially those over 55 years of age, identified by the audit as having been on benzodiazepines on a long-term basis, to withdraw from treatment...

Many patients have been on these drugs for anything from 1 to 40 plus years. One therapist supporting hundreds of patients? This is progress? This is effective action? But Gul Root seems to feel no sense of irony in sending out this message. She apparently feels it is something to feel pleased about. And who is supporting those whose addiction has ended but whose drug-induced

disabilities now rule their lives? The answer to that of course is no-one. The fact that many are disabled after long-term addiction is something that the DH does not want to acknowledge or think about. Neither does the DWP, but perhaps the two departments have made a pact that if neither thinks about it or acknowledges it, the disabilities will dissipate – become in essence non-disabilities. And if officialdom at the centre, or indeed the drug companies, don't recognise a symptom or disability then doctors don't recognise it either. Professor Ashton had this to say on the DH understanding of the benzodiazepine 'problem' and its effects:

"Withdrawal symptoms can last months or years in 15% of long-term users. In some people chronic use has resulted in long-term, possibly permanent disability." 2003

She isn't of course the only medic to have discovered benzodiazepine disability but so far, judging by its actions the DH may not have.

And

"I don't think the powers that be...have any idea of what goes on in the lives of individuals, who through failures of the present system, are driven outside the system to seek advice from poorly funded support groups and organisations like this one."
Bristol and District Tranquilliser Project AGM October 2005

Very few chronic users receive any recognition through disability benefits, it being very much a lottery and decided by those who are members of the class which committed the assault on health in the first place. Rather than help the iatrogenically disabled in fact, it seems the DWP with a little help from the DH, may take steps to take away what benefits they do receive.

The present Minister of State for Local Government, Phil Woolas has stated on several occasions that he is convinced that the whole tragedy of benzodiazepines has been deliberately swept under the carpet by government and at a benzodiazepine conference in Oldham in 2004 he went further. He said then that he believed there was an organised government cover-up of the last four and a half decades. Campaigners are fully aware of the truth of this, meeting as they do with consistent illogic and arguments that amount to untruth and avoidance.

The core question is – who is the government when it comes down to tranquillisers?

The nub of the crime against humanity that the DH has committed, is that it has stood by for nearly half a century and allowed a great many thousands of people who were not sick to be turned into people who were very sick - many severely and permanently. Many of these people had not just their health taken away from them but also their relationships, their jobs, their security, their homes. Home Office figures, no longer collected it seems, show clearly that a great many have died because of DH inaction. The inaction continues and so does the impact on people. Withdrawal for those who are brave enough to succeed, usually without help, is not the short story that the DH maintains that it is – it has a preface and a sequel. It may be comforting for those in the Department to maintain a belief that benzodiazepines are a story of health-need met by prescription and a return to health when the prescription ends. But that is a fiction for many. The question is does the department really believe that? Is it more a handy creed that lays no blame on manufacturers, doctors or the NHS as a whole?

Few if any, are so severely restricted by anxiety, as to qualify for the risk long-term benzodiazepine prescriptions carry. Indeed it is doubtful whether any rational benefit to the patient - risk to the patient analysis could ever produce a statistical weighting in favour of accepting the negative cost. The

former President of the Royal College of Psychiatrists, Mike Shooter accepts that there are over two hundred reported side-effects associated with benzodiazepines, and many of these are not minor by anybody's understanding. But no-one would ever know this talking to a GP, reading a drug company data sheet or a supposedly informative patient information leaflet. Anything remotely serious that is cited or admitted, is described as rare and unusual – anything else is not scientifically proven. It is not difficult of course for a reported symptom to be scientifically unproven when nobody seeks to discover the proof – an aspect of the NERO defence as cited by Charles Medawar –

No evidence of Risk is Evidence of No Risk.

The official non-acceptance and lack of real information to doctors regarding benzodiazepine-related side-effects has yet further impact on the patient – polypharmacy.

All drugs carry risks is the new mantra of Pharma, prescribers and government, when the downside of drugs becomes apparent. This is of course a drug company formulated defence in the new world of stated medical openness. It is a way of deflecting criticism of the damage their products do by enshrining patient responsibility - the patient should have been aware in advance. It does not matter that the doctor did not tell him of possible dangers or that Pharma is constantly emphasising the health benefits of its products - he should have been imbued with a natural awareness that all drugs are dangerous and that by taking one he was taking personal responsibility. This message carefully avoids responsibility attaching to doctors, regulators and primarily drug companies. For drug companies it pushes away the necessity to be honest and open or to look beyond marketing strategies for the benefit of shareholders. Pharma has traditionally blamed the patient first and if that fails then blamed the doctors. And what goes around comes around. The sad element in the history of drug tragedies is that the producers of those tragedies continue to be held up as honest providers of benefit to mankind, no matter how much evidence of their true behaviour emerges. But then perhaps the truth lies in the oft repeated line from government, summed up by the Rt Hon Jane Kennedy, Minister of State for Quality and Patient Safety, following the recommendations of the Health Select Committee in September 2005:

“The pharmaceutical industry is of enormous importance...to Britain...It is in all of our interests that the industry maintains its currently strong position.”

Benzodiazepines lead to much other drug prescription – addictive antidepressants, acid reflux drugs, IBS drugs, anti-psychotics, addictive drugs for insomnia (Z drugs or other benzodiazepines), addictive and other pain killers, blood pressure medication, skin complaint medication etc etc. Most of these carry high risks. So from a position of non-drug ingestion the patient gradually moves into an iatrogenic high risk category.

Kent Woods MHRA Chief Executive said in 2004:

“Our prime responsibility is to ensure we protect public health. These are aims the industry (pharmaceuticals) shares...”

There is no evidence of this when it comes to benzodiazepine addiction.

It wasn't until 1996 for example that drug companies which produce benzodiazepines, included references in their product data sheets - the owners' manual for doctors—that they were highly addictive. The DH was quite happy to accept this gross malfeasance as it is quite happy now to see

the words addiction or dependence excluded from PILS, accepting the self-serving logic of manufacturers that if these words were included, patients would be unwarrantably alarmed.

Manufacturers have a long history of fighting every attempt at control of benzodiazepines from the 1960s onwards here and abroad.

Harold Pinter in his 2005 Nobel Laureat Acceptance Speech asked if conscience still existed today. There is no doubt the Department of Health and those within it who are concerned with the benzodiazepine question should seriously address that point. The strategy the DH has employed against critics and users of benzodiazepines over the years has been masterful. It has certainly worked and it has worked on several levels which this letter explores. The brilliance of the strategy has for some time, centred around the offering of no official defence against individual claims of damage. This course has been pursued for many years now for the simple reason that there is no defence against existing research that shows the health damage that benzodiazepines cause. And in the brave new world of evidence-based medicine, there simply is no evidence that benzodiazepines cure anything. Instead, as mentioned earlier, the DH has issued statements and these have been designed to muddy the reality.

The policy of departmental persuasion and obfuscation has worked. Even the European Commissioner for Health seemed to have been persuaded by the official line when Barry Haslam through Chris Davies his MEP, took the matter to the Commission. This was the letter he received from David Byrne:

David Byrne

Member of the European Commission

Brussels 7.03.2004 D/000377

Dear Mr and Mrs Haslam,

Following our 4 February meeting on the subject of benzodiazepines, I had asked my officials to advise me on the state of play at UK and EU level. I understand that you have also subsequently spoken briefly to my officials.

The many moving letters in your dossier clearly demonstrate that the long-term use of benzodiazepines can lead to great suffering for the individuals involved. However, from the evidence available to me, it is clear that the regulatory authorities are aware of the issue of benzodiazepine dependence and their long-term adverse effects, and have been taking action on this.

I understand from this review that the issue of benzodiazepine dependence and their longterm adverse effects have been under examination for at least fifteen years. In the UK, for example, the Committee on Safety of Medicines has looked at the safety of these products on a number of occasions, and issued guidance on safe prescribing in 1988. This has since been kept under review. Doctors in the UK have been reminded on various occasions about safe prescribing and the risk of dependence. Authorised product information (for healthcare professionals and patients) contains clear warnings.

Indicative of the concerns which you have raised, Sir Liam Donaldson, the UK's Chief Medical Officer, issued a Communication to Doctors regarding Patient safety and the use of Benzodiazepines following the advice of the Committee on Safety in Medicines in January 2004. This information explicitly sets out prescription advice regarding limited periods, reduced use and directs against their prescription for "mild anxiety". The, issue of

substance mis-use is highlighted in this advice which also refers to the importance of instalment dispensing to minimise access for addicted patients.

It appears to me that this advice provides a solid basis for tackling this issue. It also suggests that the solution to this distressing problems lies in effectively implementing this advice at local level. This is clearly an issue to be pursued by the national authorities who have legal competence for the organisation and delivery of health services and which is outside the competences of the European Community.

I am grateful to you for drawing this matter to my attention. As was agreed, I enclose for your information the names of patient organisations which you may wish to contact.

I am copying this letter to my colleague, Mr Erkki Liikanen who is the Commissioner with leading responsibility for pharmaceutical policy.

May I once again express my appreciation for your personal dedication to the well-being of your fellow citizens - it is clearly making a real difference.

Yours sincerely



David Byrne

Patient organisations in the United Kingdom

Prodigy, hypnotic and anxiolytic dependence and insomnia www.prodigy.nhs.uk

CITA Council Of Involuntary Tranquilizer Addiction www.24dr.com/reference/contact/uoup/cita.htm

Cc: Commissioner E. Liikanen

Encl. Communication of January 2004 from Sir Liam Donaldson

So those outside personal experience of benzodiazepines have been convinced that the DH addressed the 'problem' of tranquillisers long ago in serious and timely fashion:

"The Seroxat scandal is one of gigantic proportions, which affects millions of people. There has been over-prescribing and misprescribing of this antidepressant on a scale equalled only by the over-prescription of tranquillisers 40 years ago."

Paul Flynn MP
Seroxat Debate 23 February 2004 Hansard

"For an awful period in the 1960s and 1970s, diazepam—or valium—and other similar drugs were

prescribed like smarties. That caused great distress and did very little good.”

Paul Flynn MP

Debate on the Pharmaceutical Industry Westminster Hall 8 December 2005

If even Paul Flynn who is known to be a long term critic of the pharmaceutical industry, with a good grasp of its machinations, can make statements like these, then the strategy has obviously worked.

Benzodiazepines have often been cited in passing as a scandal but it is the nature of that scandal and its longevity that are truly worthy of note. And the most notable aspect of both nature and longevity is the cleverly and carefully rehearsed official recognition without recognition that benzodiazepine addiction has received. To be a scandal an event has to be officially recognised as a scandal and tranquilliser damage never has been. A scandal requires palliative measures, inadequate or late though they may be. One wonders why there is an absence of such measures – but only momentarily.

Those with the experience of the continuing benzodiazepine ‘problem’ hold rather different views to the belief expressed by Paul Flynn:

“There is a fallacy in the Western world that the benzodiazepine problem was addressed in the 1980s, particularly by the high profile campaigns, the That’s Life programme and other legal actions. In fact, the prescription guidelines have not been enforced for the past 20 or 30 years.”

Phil Woolas MP

Evidence to the Health Select Committee 25 November 2004

“We have the first primary care trust funded treatment service for withdrawal from benzodiazepine addiction, but we are dependent, as a national organisation, on voluntary funding from individuals. In particular, our efforts to bring legal cases have been hampered by the lack of legal aid, the lack of funding for advocacy, and of course the enormous resources of the particular companies that have provided benzodiazepines over the last 30 years.”

Phil Woolas MP

Evidence to the Health Select Committee 25 November 2004

Claims by politicians that the present system of drug approval and regulation protect public health are surreal in the extreme when viewed against the history of benzodiazepine addiction. Over the years for example, psychopharmacologist, Professor Malcolm Lader OBE, DSc, PhD, MD, FRC Psych, FMedSci - a man not unqualified to judge, had these things to say about benzodiazepines:

1978 He described benzodiazepines as the opium of the masses.

1981 He said there was an epidemic in the making.

1982 He said he had evidence of shrunken brains from scans of long-term users.

1988 He said benzodiazepine addiction was the biggest medically-induced problem of the late 20th century.

1991 He said no real attempt is made to help addicts withdraw. Government should set aside funds.

But government ignored the epidemic in the making, until it could ignore it no longer following media revelations. Government then ignored the physical damage benzodiazepines caused, and stuck rigidly to a message that prescriptions had been solely for anxiety, knowing that to label a condition as psychiatric gave absolution from responsibility for all except the patient. Government further refused to acknowledge benzodiazepine addiction as the scandal it had become and as part of that refusal it did not set aside funds to assist the afflicted. As part of the policy of damage limitation, government preferred the views of experts such as Professor David Nutt of Bristol University, a former GSK shareholder with financial links to Wyeth and Roche who was still saying at the end of the 20th century:

“The case for benzodiazepine dependence causing real damage has not been made.”

“Some patients appear to require maintenance benzodiazepines.”

Professor David Nutt – Home Office Expert and Adviser, Drugs Regulator

In respect of his expressed expert views, these are some of the wide variety of possible effects of long-term benzodiazepine prescription when withdrawal is attempted. It is far from unknown for patients to experience the majority of these symptoms –

Abdominal pains and cramps, Agoraphobia, Anxiety, Breathing difficulties, Blurred vision, Changes in Perception, Depression, Distended abdomen. Dizziness, Extreme lethargy, Fears (uncharacteristic), Feelings of unreality, Flu-like symptoms,

Heavy limbs, Heart palpitations, Hypersensitivity to light, Indigestion, Insomnia, Irritability, Lack of concentration, Lack of co-ordination, Loss of balance, Loss of memory, Muscle/Joint aches and pains, Nausea, Nightmares, Panic attacks,

Rapid mood changes (crying one minute and then laughing), Restlessness, Severe headaches, Shaking, Seeing spots, Sore eyes, Sweating, Tightness in chest, Tightness in the head (feeling a band around the head)

Aching jaw, Weight gain or loss, Constipation, Depersonalisation (a feeling of not knowing who you are) Diarrhoea, Difficulty swallowing, Feelings of the ground moving, Hallucinations (auditory and visual),

Hyperactivity, Hypersensitivity to sound, Incontinence or frequency or urgency, Increased saliva or dry mouth, Numbness in any body part, Outbursts of rage and aggression, Paranoia,

Painful scalp, Persistent unpleasant memories, Pins and needles, Rapid body changes in temperature, Sexual problems, Skin problems, Speech difficulties, Sore mouth and tongue, Suicidal thoughts, Brain damage

Blackouts, Bleeding from nose, Burning sensations, Craving for pills, Discharge from the breasts, Hair falling out, Haemorrhoids, Hypersensitivity to touch, Rectal bleeding, Sinus pain, Seizures, Sensitive or painful teeth and/or gums.

For a significant percentage of patients varying numbers of the symptoms they experience in withdrawal will stay with them for many years and for some it will be permanent

The unwanted side-effects of actually taking the drugs once addicted are also many and varied and the single word dependence does little justice to the reality. Common symptoms are:

Impaired memory and concentration, Being unable to respond emotionally in your usual manner, Feeling cut off from people and/or your feelings, Depression, Loss of balance, Impaired motor co-ordination, Mood swings, Irritability and outbursts of rage.

Some of these symptoms explain clearly why patients have experienced social effects above and beyond the strictly medical and why the long term addicted may never escape the effects of the scandal. Government prefers not to examine this question at all.

People suffering benzodiazepine withdrawal feel like they are always sick and withdrawal occurs while patients are still taking the drugs (tolerance). Addicted patients have little self-confidence and have reduced intellectual skills. Often they leave their employment because they cannot cope, are unable to relate and dread speaking on the telephone. They are afraid to be left alone. They often ask people to stay with them and simple activities like going shopping and making even minor decisions become almost impossible tasks.

Because they are psychologically and physically dependent on benzodiazepines, people feel unable to cope or survive without taking their tablets. As they have not associated their increasing decline in physical and mental health with their long-term benzodiazepine use, they rely increasingly on the drugs to help them cope. They will often take an extra tablet to deal with any vaguely stressful event. Without information on the long-term effects of benzodiazepines, people assume that their mental and physical distress is related to their original problem.

The risk/benefit equation with benzodiazepines is obviously badly calculated but is still part of official camouflage. It is for reasons such as the ones listed below that many thousands have gone through the terrible physical agonies listed and many in addition have lost their security and place in society.

**Bereavement.
Emotional upsets.
Nursing sick wife after
an operation
After an operation.
Husband's accident.
Socialising.
After-flu virus.
Dry eyes.
Alcohol problem.
Alcoholic father.
Sex abuse.
Stomach trouble.
Hysterectomy.
Business problems.
Handicapped child.
Shiftwork.
Bankruptcy.
Thyroid problems.
Demanding mother.
Driving test.
Scared of dying.**

**Asthma.
Bad fall.
Rugby injury.
Rape.
Car crash.
Headaches.**

**Mastectomy.
Interview nerves.
Retirement.
Dizziness.
Abortion.
Stroke.
Active/crying baby.
Shyness.
Childhood insecurity.
Isolation.
Family problems.
Floater in the eye.
Broken neck.
Changed job.
Violent husband.
Infertility.
Fatal illness.
Disc trouble.
Divorce.
Menopause.
Prison.
Cystitis.**

**Cat died.
Lack of confidence.
Redundancy.
Homelessness.
Hay fever.
Mother committed suicide.
Vertigo.
Jury service.
Palpitations.
Work pressure.
Moving house.
Loss of hearing.
Cooker blew up.
Claustrophobia.
Illness.
Post-natal depression.
Exam nerves
Back pain.**

This is what the typical patient leaflet has to say to patients embarking or already embarked on benzodiazepine ingestion:

APS

PATIENT INFORMATION LEAFLET

DIAZEPAM TABLETS BP

Please read this leaflet carefully before you take these tablets. It briefly outlines the most important things you need to know. If you want to know more about this medicine, or you are not sure about anything, ask your doctor or your pharmacist. The name of your medicine is Diazepam.

WHAT IS DIAZEPAM?

Diazepam tablets contain 2 mg, 5 mg or 10 mg of the active ingredient Diazepam Ph. Eur. The other ingredients are lactose, powdered cellulose, maize starch and magnesium stearate. The 5 mg tablet also contains the colours quinoline yellow (E104) and sunset yellow (E110). The 10 mg tablet contains the colour indigo carmine (E132). The product is available in packs of 28 tablets

See outer packaging or the pharmacy label for contents i.e. the number of tablets.

Diazepam tablets belong to a group of drugs called benzodiazepines which promote sleep and relieve anxiety by altering brain activity concerned with emotion.

The Marketing Authorisation holder and company responsible for manufacture is Approved Prescription Services Limited, Eastbourne, BN22 9AG England.

WHAT IS DIAZEPAM USED FOR ?

Diazepam tablets are used for the short term (2 - 4 weeks) relief of severe anxiety and tension, to relax muscles and to encourage sleep. They may also be given to relax or sedate people undergoing certain uncomfortable medical procedures. Ask your doctor or pharmacist for additional information.

BEFORE YOU TAKE DIAZEPAM

Are you sensitive to any of the ingredients in the medicine, listed above ?

Have you suffered a reaction to benzodiazepines before ?

Do you have long term kidney or liver disease ? Do you suffer from severe respiratory problems ?

Do you suffer from Myasthenia gravis (a disorder where muscles become weak and tire easily) ?

Are you taking any other sedatives e.g. temazepam, or anti-epileptic drugs e.g. phenytoin or phenobarbitone ? Are you taking cimetidine or omeprazole (for stomach ulcers) or rifampicin (for tuberculosis) ?

Have you had problems with alcohol or drug abuse ?

Do you suffer from depression or any other psychiatric problems ?

If the answer to any of these questions is YES, do not take Diazepam before consulting your doctor or pharmacist.

Do not take this medicine if you are pregnant, might become pregnant, or are breast-feeding.

If your doctor has decided that you should receive this medicine during late pregnancy or during labour, your baby might have a low body temperature, floppiness, and breathing and feeding difficulties. If this medicine is taken regularly in late pregnancy, your baby may develop withdrawal symptoms.

Your tablets may make you feel drowsy or dizzy. Do not drive or operate machinery until you are used to these tablets.

You should avoid alcohol whilst taking these tablets, as it may increase the sedative effect of the drug.

TAKING DIAZEPAM

The tablets should be swallowed with a drink of water.

The usual dosage instructions are given below:

Anxiety: 2 mg three times daily. If necessary your doctor may increase the dosage.

Trouble in sleeping: 5 - 15 mg before going to bed.

Muscle spasm: Adults: 2 - 60 mg.

Children: 2 - 40 mg.

For both adults and children the dose is dependent on the symptoms, your doctor will decide on the correct dosage.

Pre-medication: Adults: 5 - 20 mg.
Children: 2 - 10 mg.

Your doctor will decide on the correct dosage.

Elderly and Debilitated

(very frail) patients: Normally the starting dose is a half of the ordinary adult dose.

Long term use of diazepam is not recommended. Treatment should not normally last more than 4 weeks. Your doctor has decided the dose which is suited to you. Always follow your doctor's instructions and those which are on the pharmacy label. If you do not understand these instructions, or you are in any doubt, ask your doctor or pharmacist. You should continue to take these tablets for as long as your doctor tells you to. If you forget to take a tablet, take one as soon as you remember, unless it is nearly time to take the next one. Never take two doses together. Take the remaining doses at the correct time.

If you see another doctor or go into hospital, let him or the staff know what medicines you are taking. If you (or someone else) swallows a lot of the tablets all together, or if you think a child has swallowed any of the tablets, contact your nearest hospital casualty department or your doctor immediately.

Do not stop taking your tablets suddenly. If you do, you may suffer from withdrawal symptoms. If your doctor decides to stop your tablets, he/she will reduce the dose gradually.

When you stop taking Diazepam, you may feel anxious, depressed and restless and have difficulty sleeping. You may also experience sweating and diarrhoea. If this happens go to your doctor for advice.

AFTER TAKING DIAZEPAM

Diazepam, is taken by many patients without any problems. However, like many other medicines, it may occasionally cause side effects in some people. These may include blurred vision, dizziness, unsteadiness and loss of co-ordination.

Rarely, confusion, feelings of excitement or depression, aggressive outbursts, skin rashes or itching, headache, stomach upset, changes in sex drive, jaundice (characterised by the yellowing of the skin or the whites of the eyes), difficulties in passing urine, low blood pressure and blood disorders (which may be characterised by pallor, fever or chills, sore throat, ulcers in your mouth or throat, unusual bleeding or unexplained bruising). If you have these or any other effects, whilst taking Diazepam tell your doctor immediately.

Another side effect is daytime drowsiness. However, this effect is often mild and usually wears off after a few days treatment. If it is severe or lasts for more than a few days, tell your doctor.

Also, if you feel unwell in any other way, tell your doctor.

It is more than doubtful that the present review of patient leaflets will significantly alter the almost complete fiction set out in the present leaflets. How would it be possible to include realistic warnings, not hedged with 'ask your doctor', or mentioning the true reason for 2 to 4 weeks prescription 'normally', or listing the real dangers of side-effects? To do this would explode the carefully constructed official history of benzodiazepines and the myth of available palliative services. It is a real question as to what medical magic GPs or psychiatrists would employ to deal with such things as drug induced brain damage, other drug induced physical disabilities or indeed lost families, lost employment, homes and futures. Perhaps it is an undisclosed official realisation of the real effects

associated with benzodiazepines that underlies the rigid and patently false statements - that there is help out there for patients, available in Primary and Secondary settings.

The story of benzodiazepine addiction is one of drug company power and influence in government and the healthcare system. It is one of a regulatory system that did not work even after the Thalidomide tragedy and of government dependence on that failing system.

When the real impact on people of tranquillisers was forced onto government and the regulatory agencies by patients and the media, the story became one of political calculation about possible fallout. The considerations included political cost, economic realities, the image of the NHS, the lack of alternatives to benzodiazepines and the unique position of doctors as independent contractors.

In order to marginalise the scandal and avoid responsibility for the damage, a policy of seeming action and public reassurance was instituted. A list of approved responses was drawn up to respond to critics, patients and the media. It did not matter what information was laid before government departments, the response was the same preformulated message and if this avoided any reference to points being made, it did not matter. To engage in debate about realities being described was seen as a possible opening of the flood gates to discovery. The drug company line of blaming the patient where possible was followed and as an essential part of this, it was seen as necessary to stick rigidly to references to anxiety – the medical reason for which the drugs had been licensed in the first place. It did not matter that benzodiazepines had been prescribed by the independent contractors for every social ill and condition under the sun – the line of departments and agencies was that all prescriptions had been properly aimed at anxiety. This was seen as a strength in future strategies. A psychiatric label is permanent and has unique connotations in the public mind.

If at any time it was impossible to maintain the line that a prescription had been properly issued for anxiety, patients were referred to their doctor's responsibility and stories in the media giving the impression that there were a few (rather than many) ignorant doctors damaging health and ignoring official advice, were seen as fortunately missing the point.

The DH, its regulatory agencies and government generally, slowly began to cover the tracks by issuing guidance to doctors and later to local health bodies on appropriate prescribing. The setting up of PCTs, SHAs, NICE and the guidance given to doctors by the CSM and others later, fortuitously meant that direct responsibility was now avoidable – all criticism and claims could now be redirected to doctors and local health authorities. But in addition it also meant that the entire impression could be given to the media and others, that government had acted responsibly. Ironically it also enabled minister Rose Winterton at the DH in 2004 to continue to tell campaigners that the priority of government was to prevent addiction occurring in the first place. The issuance of guidance and the making of statements costs very little money of course.

But how is a priority defined? Professor Ashton and campaigners told the minister that there were still more than 1.2 million medical addicts in the UK, with around 180 per GP practice. The minister was told that withdrawal facilities were virtually non-existent (for those legally addicted). Many of these addicts became addicted years ago and their doctors now would therefore feel able to disclaim responsibility. This of course is the most successful aspect of the long-term avoidance and cover-up

by successive governments and the drug companies. By the use of pre-planned strategies, medically-induced benzodiazepine addiction has become old news and the present government has been able to persuade itself that it has fulfilled any responsibilities it might have. Ironically it may not realise that to benzodiazepine veterans, the strategies and statements at present being employed with SSRIs are also old news.

So governments in the past did not wake up to what tranquilliser addiction was doing to the population until they considered it to be too late to address it, and so for political reasons there was very little help available. Now the present government is easily able to persuade itself that the past has moved away and the plethora of advice its agencies have issued covers all eventualities. There is still no help, either for those addicted years ago, or for those more recently legally addicted, but now central government no longer feels direct responsibility. If help is not available it is the fault of SHAs and PCTs and doctors have the primary responsibility.

But what real responsibility is there? And what should responsibility mean in the field of drug induced health and social destruction? What protection has the patient really got?

In the late 1980s a group action began involving thousands of claimants, which cost the Legal Aid board around £45 million. The resources of the defendant drug companies Roche and Wyeth made certain that the cases dragged on and were eventually ended by legal manoeuvres.

The conservative government of the time made the decision that this would never happen again.

They did two things –

1. They set up the Legal Services Commission to replace the Legal Aid Board. The LSC acts as a quasi court. After determining income levels, the LSC calculates the amount of likely damages before determining whether the amount of legal aid would exceed that figure. Since the law is based on the now dismissed reality of a few months of withdrawal and problem over, the legal aid figure required always exceeds the damages figure. Therefore there is no legal aid.

2. To offset (they said), a likely reduction in access to justice, the government introduced the No Win No Fee system. But this did not lead to access to compensation for tranquilliser addicts for the simple reason that such cases would prove intractable and costly given the resources of drug companies.

The inability to claim compensation from a pharmaceutical company is unfortunately matched by an inability to sue a doctor.

This fact of life was covered in a story entitled:

VERY DIFFICULT TO SUE A DOCTOR BBC NEWS MARCH 2002

Anne Alexander of Alexander Harris had this to say -

...The other problem, she says, is that changes to the legal aid rules two years ago made the process of suing doctors more difficult...

"There is now no longer legal aid available and consequently the client has only two ways of dealing with it... Either to pay or to persuade a solicitor to take it on, on a no win no fee basis.... it is extremely difficult to find a solicitor to take it on, on a no win no fee, or one who would be happy to let you risk your own money on such a case.

So that leaves you little option but to try to find your way round the NHS complaints procedure.

The biggest hurdle can be the fact that the first person you have to raise the complaint with may be the doctor himself."

Complaints must be raised locally first.

But the government's own evaluation of the procedure found that staff who dealt with complaints were sometimes unhelpful, aggressive or arrogant...

More recently the realities of legal aid have been illustrated in the Vioxx cases. On November 29 2005 the Guardian produced an article on the subject:

"One of Britain's leading QCs warned last night of a "serious risk" that people injured by faulty drugs will no longer be able to mount compensation claims in the British courts...

...Martyn Day, a solicitor who acts for 200 claimants, said they appeared to be caught in a legal limbo barring them from seeking compensation. They have no funding to sue in Britain after being refused legal aid and they have also been denied the insurance they would need to pursue a claim on a no-win, no-fee basis...

...Mr Day said the case was the strongest against a pharmaceutical company in 10 years, because it was supported by "gold standard" scientific studies showing a significant risk of adverse effects compared with similar drugs...

He said the failure to get funding for the case spelled "the end of litigation against drug companies in the UK," adding:

"If this case can't get into the courts here, then I don't know what will."

Lord Brennan, who has acted for claimants in some of the biggest drug cases, said there was "a serious risk" that compensation claims against drug firms could no longer be brought in Britain because of restrictions on funding...

...One claimant, Vivian Wyatt, 57, of Highbridge, near Bridgewater, Somerset, said she took Vioxx for four years until her GP told her not to take it any more because of liver damage. A week later she had a heart attack. Now disabled, she said:

"The only way I could fund it [the case] is by selling my house and all my possessions."...

English law cannot deal with drug damage. We have the situation of a great many people with lost jobs, lives and health who cannot get compensation from a drug company, cannot get compensation from a doctor and cannot get government to recognise the need for assistance following the massive legal overprescription of addictive drugs. The law then cannot protect the patient from government and regulatory inaction, drug companies or doctors who persist in clinical judgement.

Other things which should protect the patient – honest and scientific data sheets, honest and fully informative PILS, the NHS Complaints procedure, the BNF, the GMC all fail when it concerns tranquillisers and hypnotics.

Just as statements on benzodiazepines from health sources are ultimately empty of meaning, so too are statements from politicians who achieved a position where they could have altered the situation.

These are two letters to Barry Haslam, one from David Blunkett MP and the other from Paul Boateng MP on the subject of Benzodiazepines written as you see some time ago. Needless to say the ‘national scandal’ has not been addressed. Neither has ‘justice’ been obtained.



HOUSE OF COMMONS
LONDON SW1A 0AA

DAVID BLUNKETT MP

Shadow Secretary of State for Health
and Member of Parliament for Sheffield Brightside

24 February 1994

Dear Mr Haslam

Thank you for your recent letter regarding Benzodiazepine Tranquillisers.

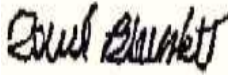
Dawn Primarolo and myself have been taking up cases and have advised on how best the groups involved might organise a parliamentary lobby and keep attention on these issues.

We have also tried to assist through both Parliamentary Questions and raising the matter on the floor of the House, in pushing the Government to accept its own responsibilities and to take action now to ensure that it does not happen again.

This is something we will be returning to both in the House and in terms of our own future policy development.

I am passing your letter to Paul Boateng who, as the legal affairs spokesman, has specific responsibility for the litigation side of what is a national scandal.

With all good wishes



David Blunkett MP

Shadow Secretary of State for Health



**HOUSE OF COMMONS
LONDON SW1A 0AA**

PAUL BOATENG MP

25 April 1994

Dear Mr Haslam

Your letter to David Blunkett has been passed to me. The case of the Ativan victims is one on which I have been very active in recent months. I am therefore, of course, always glad to receive any research papers to supplement the large number of such documents that I have in my possession. I thank you for those which you have sent to me thus far and would be grateful for anything further.

Clearly, the aim of all involved in this sorry affair is the provision of justice to the victims of these drugs.

Yours sincerely,



Paul Boateng MP

The Department of Health and its agencies has demonstrated a singular lack of understanding of addiction over the years – illegal addiction is understandable but legal addiction is not apparently. A

clear example of this was set out on 13 May 2004 by Gul Root on behalf of the the Department. She said there was a plan to –

“implement instalment dispensing of benzodiazepines for the management of addiction over the next year and (the Department) are currently exploring regulatory and other changes required to make it possible...”

...Instalment ‘dispensing’ allows a single prescription to be written for a patient whilst allowing the pharmacist to dispense the medicine to the patients over a number of days. This avoids the need for a separate prescription for each instalment dispensed, making it simpler for a prescriber to limit the amount of medicine a patient has dispensed in one go. This also has benefits for the patient as they do not have to go to the GP each time they need their medicine dispensed. This will be particularly useful for addicted patients on benzodiazepines who may be liable to misuse their medicine.”

This represented an official adherence to the self-serving belief that patients misuse benzodiazepines.

This belief ignores the addictive nature of these substances and the phenomenon of tolerance withdrawal - both scientifically established and well understood by the formerly addicted. It is not patients who misuse these addictive substances, it is the prescription for addiction that abuses the patient. It is doctors who have been misusing the patients through their prescriptions for nearly half a century. It is the government and regulatory authorities who have been abusing the trust placed in them by the population to safeguard their health.

People who have taken benzodiazepines from a doctor’s prescription have their mental, emotional and physical capabilities compromised by the tablets. The substance produces craving in the body’s systems. Increased amounts of it are needed to produce the same effect of equilibrium in the body’s systems. This continual upward spiral produces the only level at which the unfortunate addicted ‘patient’ can continue to function at what he or she has come to accept as ‘normal living’.

‘Normal,’ for the many thousands of people ingesting these prescribed tablets in good faith, is in reality a gross reduction in the quality of their life. With mental, physical and emotional capabilities restricted, these patients find their world contracts, as they become unable to solve problems in life, unable to empathise with family and friends, unable to be interested in the world outside, developing obsessions, developing agoraphobia, prone to irrational outbursts of rage, beset by inexplicable physical symptoms – which doctors either dismiss as psychiatric, or prescribe other drug treatments for, or make investigative hospital appointments for. Conditions mimicking arthritis, ME and MS are three of the other well-documented consequences of taking benzodiazepines and its inescapable tolerance withdrawal effect. Evidence of the genuine conditions is frequently and it would seem mystifyingly, never found in people addicted to benzodiazepines. And the ‘mystifying’ conditions often disappear if withdrawal is successfully completed

A doctor’s responsibility for ruining so many people’s lives effectively ended with his signature on the prescription. Now the DH were outlining plans to neatly shift the results of the irresponsible initial and repeat prescribing onto pharmacists. Now under this plan, even patients who, because of the drug’s intrinsic effects, did not have the mental determination or emotional stability and support network to even think of the idea of withdrawing, would be standing in the pharmacy at frequent intervals, seeking more of the neuro-toxic substance to maintain their much reduced quality of life.

The proposal meant that patients were to be further assaulted by a convenient stigmatisation as drug addicts, something which in fact was a direct result of government policies over 45 years. This included a refusal to control doctors' prescribing and a refusal to accept patient evidence over manufacturer's hyperbole.

It takes a person who had a strong sense of self-worth before starting on tranquillisers to withdraw (and from subsequent anti-depressants frequently prescribed to try and minimise the depression caused by benzodiazepines). It needs the ability to take advantage of any moments of clarity in which they can contemplate a life without their customary bedside or pocket bottle of tablets. Through no fault of their own, that bottle of tablets became their life support system.

It takes a person with a lot of willpower, who can live through the gigantic upheaval to their life in withdrawal. Rebound insomnia, the intense muscle and joint pain they may experience, the baffling sensory sensations affecting nerves all over the body, sleep apnoea, the irrational outbursts of rage, the nausea, the mood swings, are just a few of the horrendous and well-documented benzodiazepine withdrawal symptoms.

It takes a very strong family or strong support network to endure this journey through the unknown with the iatrogenic addict. If the whole process is successful and a drugs free personality reappears, they and the recovered addict have to learn to relate to each other again. Repairing relationships can take years if it is possible at all. Withdrawing from the drug can take years. There is the possibility of failure, as with withdrawing from any addictive substance.

So how would instalment prescribing help these people - those determined to take the plunge and withdraw? More importantly - what good would it do for those who could not face withdrawal? With the drugs controlling thought and physical need twenty-four hours a day, what benefit would be conferred by being forced to stand in chemist shops open only during the day - for drug relief, stigmatised as an addict in need of a controlled fix?

Multiple millions of government money is spent to benefit users of illegal drugs, increasingly including benzodiazepines. The list of government activities in regard to legal addicts is pitiful, after 45 years of damage to the innocent. If alterations to regulation could be considered to allow instalment prescribing, why cannot it be considered to control doctors' prescribing? If the daily creation of new iatrogenic addicts by uninformed doctors was actively prevented, the pleas for money to be put into support networks would gradually cease.

It seems then, that in the Department of Health, benzodiazepine addiction is little understood and convincing policy-makers that it is not patients who misuse the drug, but the drug that misuses the patients, has proved impossible. The only way it seems that understanding is reached is through the personal taking of tranquillisers for an extended period. Department officials could write a diary of how their dose escalated and things in their lives changed. They would have to ensure of course that someone was making sure they continued it, because it would not be long before even keeping a daily diary became an intolerable task.

Is there a defence for the incalculable health damage inflicted on UK citizens through benzodiazepines? Professor Heather Ashton had this to say in 2005:

"How the dependence potential of benzodiazepines was overlooked by doctors when it was clear they could replace their predecessors such as barbiturates is a matter for amazement and casts shame on the medical profession which claims to be scientifically based."

And

“The similarities between benzodiazepines and barbiturates was ignored despite a few warning voices (including my own, which went unheard)...Eventually, in the early 1980s, controlled experiments...by Malcolm Lader, Peter Tyrer and others, demonstrated beyond doubt that withdrawal symptoms from regular therapeutic doses of benzodiazepines were real.”

In 1990 Social Audit published the book *Power and Dependence*. Written by Charles Medawar, it was a clear analysis of the history of benzodiazepines up to the late 1980s. Its description included the following:

“...the risks [of benzodiazepines] were always obvious and...the providers of medicine between them, readily let this happen.”

Government, civil servants and regulators, maintaining silence, eschewing debate and any attempt to verify patient claims, have been avoiding all aspects of responsibility for what they allowed to happen since the first claims of harm emerged following licensing of the drugs. The gloss that has been placed on what must surely be the greatest single source damage ever inflicted by a healthcare system, has been accepted by most. But then most have never seen a withdrawing benzodiazepine addict, most have never known an addict before he became one and most have never followed the life of an addict after he ceased to be one.

Benzodiazepine damage has been and is, a great evil in the world, and how should we view the producers of that evil and those who maintained and denied it?

But as Upton Sinclair once said:

‘It is difficult to get a man to understand something when his salary depends on his not understanding it.’

Colin Downes-Grainger

Benzodiazepine Campaigner