Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

12 March 2009

Dear Ms Primarolo,

“Yet I am still astounded with the gross patronisation shown to your intelligent queries and comments. Lack of due diligence doesn't even begin to describe what they are doing here. Are they stupid, incompetent, criminal or all three?”
Stuart Jones, campaigner, on recent replies from the DoH 12 March 2009

I have just read your letter to Ms Primarolo. Keep writing Colin until you get 'sensible' answers because we all want to know the outcome of this! Clearly this issue of addicted benzo patients, in their thousands, really suffering on these mind altering addictive drugs is known to the DoH. How any person cannot want to acknowledge their suffering and not want to ease or address these very serious issues beggars belief! Where is their integrity? Where is their compassion? Do they even have any sense of what is right and what is wrong? Do they actually care as human beings? The answer is no to all my questions.

But what is clear to most people is this, these now very ill, addicted patients on prescription drugs, are being abused and ignored on every level of NHS health care. The Government has made it quite clear that these involuntary addicted patients are to be excluded from receiving proper health care that all other UK citizens and prisoners have a right to and who access health care with ease. Clearly this is discrimination of benzo patients who live within the community, (out of sight out of mind) by exclusion. How many lovely people have died through the years due to this lack of provision of proper health care and continue to die. It makes me feel so deeply ashamed to say that I am English.
Mary Baker Voluntary Benzo Counsellor 12 March 2009

Recently I have received letters from the Customer Service Centre (references 7000000378848 and 7000000391079). Neither letter answered anything but did confirm what has been clear for some time, that illegal drug advisers are in the ascendant at the DoH and the department is following a policy formulated by them; therefore patients addicted to tranquillisers by doctors are to be treated as drug abusers. The information given related principally to illegal drug abusers and not to patients.

- Claims that treatment is available in drug misuse centres are inappropriate because patients did not misuse drugs. They are also inappropriate because ‘treatment’ is not available to patients; such centres refer patients to their doctors. Data sent to the DoH presumably does not include a count of the number of patients treated, if it did it would be seen that the number of patients treated is nil or virtually so.
- Claims that treatment is available in primary care settings is wrong - even an aware and punctilious doctor can do no more than encourage and give advice but cannot prevent historical damage or the possibility of protracted withdrawal symptoms or permanent injury.
- Claims that treatment is available in secondary settings are partially true if by that is meant psychiatric hospitals, but no-one should view a psychiatric hospital as appropriate

for patients who had no psychiatric illness until they took or tried to withdraw from prescribed medication.

All letters from the DoH are a variation on the standard themes below and the first letter from the Customer Service Centre was no exception:

- "We regard dependence on benzodiazepines 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.

- First of all let me say that the Department of Health, the NHS and the various professional groups regard involuntary addiction upon benzodiazepine drugs as a very important issue... As you know, the main focus of the Department of Health's action in this area has been to try and prevent addiction/dependence occurring in the first place by warning GPs and other prescribers of the potential side-effects of prescribed medicines and the dangers of involuntary addiction.
  Rosie Winterton MP, Minister of State, Department of Health, to John Grogan MP, Professor C.H. Ashton and others January 11, 2004

How seriously does the department take the issue?

Mention is usually made in DoH letters of reminders to doctors on safe prescribing and of the advice in the BNF as though this was enough. Even the government mental health Czar Professor Appleby said in a Panorama programme a few years ago that he did not think Guidelines were sufficient. I should point out too in respect of a point made in the CSC letter that the CMO reminder to doctors in 2004 was as a direct result of campaigners' representation at Richmond House and would not have happened otherwise. The MHRA is a failing organisation as far as the collection of data on harm is concerned (see the House of Commons Health Committee report for this conclusion).

The BNF does indeed have good advice and if all doctors followed it, patient suffering in withdrawal at least, would be reduced.

BNF January 2009

4.1 Hypnotics and anxiolytics

Dependence and withdrawal

Withdrawal of a benzodiazepine should be gradual because abrupt withdrawal may produce confusion, toxic psychosis, convulsions, or a condition resembling delirium tremens.

The benzodiazepine withdrawal syndrome may develop at any time up to 3 weeks after stopping a long-acting benzodiazepine, but may occur within a day in the case of a short-acting

one. It is characterised by insomnia, anxiety, loss of appetite and of body-weight, tremor, perspiration, tinnitus, and perceptual disturbances. Some symptoms may be similar to the original complaint and encourage further prescribing; some symptoms may continue for weeks or months after stopping benzodiazepines.

Time needed for withdrawal can vary from about 4 weeks to a year or more.

But there is no official protocol for benzodiazepine withdrawal and doctors are free to follow their own practices, right or wrong. Patients have no redress against this fact. This letter I received a few days ago illustrates the point very well:

“We, the ex -benzo survivors know for sure that there is no 'proper treatment' for these involuntary addicted patients on the NHS. Take for instance this recent case of an elderly lady in her seventies, who telephoned me just last week for help because she is feeling so ill when trying to get off diazepam with the help of her GP.

This lady had been prescribed 4mg of diazepam per day, seven years ago, but now feeling very ill, so she asked her GP for help in coming off the drug. The advice given was this. Take the drug one day, then miss the next day, then take the drug on the third day, and continue like this. So this lady actioned this ad-hoc withdrawal regime and has become even more ill. Obviously her drug blood levels became unstable, and this is why she now feels so very ill. We all know that this is not the way to take benzos when trying to get off them, and that this lady has been further 'handicapped' by the incorrect advice given by her GP.

This is common practice in how many patients are treated in the NHS because GP's have not been properly trained or educated on benzo addiction illness, or of how to treat these patients who want to get off their prescribed drugs of addiction.”

NB This lady did not increase her prescribed dose and could not by any stretch of the imagination be described as a drug abuser, but the drug still made her ill eventually.

The DoH seems totally unwilling to engage with the true nature and seriousness of the addiction, either by accepting what some medical experts and patients tell it, or commissioning research to validate or invalidate the claims. The symptoms reported below show clearly what the department is not addressing in its statements.

REPORTED SIDE EFFECTS

Depression, Anxiety, Insomnia, Agoraphobia, Impaired thinking**,** Impaired memory and concentration, Inability to respond with normal emotions, Feeling cut off from people and/or feelings. Loss of balance, Impaired motor coordination, Mood swings, Irritability and outbursts of rage, Self harm, Worthless feelings, IBS, apparent ME, apparent MS, apparent thyroid problems, apparent arthritis, hypertension, skin problems etc.

REPORTED BENZO WITHDRAWAL SYMPTOMS

Some of these may be more uncommon than others but it is not impossible to suffer many of them.

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)

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.

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.

And it should be remembered, as reported by Professor C. H. Ashton, Professor Malcolm Lader and others, that for a proportion of former patients, recovery may well stay incomplete (Professor Ashton estimates 15%), which for millions of patients over 50 years is an awful lot of people.

The quotes below from distinguished academics as well as the reported symptoms above illustrate very clearly that the seriousness of benzodiazepine addiction is grossly underestimated by the DoH and responsibility for it lies with prescribers and not the patient.

- “The main characteristic of these [tranquilliser] dependent people was that when they tried to stop they didn't just get their old symptoms back, they didn't just get their old symptoms back in an exaggerated form, they developed new symptoms which they had not experienced before.” Professor Malcolm H Lader, Professor of Clinical Psychopharmacology, Institute of Psychiatry,
  University of London. In Pills We Trust, Discovery Channel, December 4-18, 2002.

- “Our clinical impression is that many patients experience symptoms on reduction or withdrawal of their benzodiazepine medication, and that whilst these symptoms somewhat resemble those of anxiety they differ qualitatively and are often more severe than those for which the medication was originally given." C. Hallström, M. Lader, Benzodiazepine Withdrawal Phenomena, Int. Pharmacopsychiatry, 1981, 16, 235-244).

- "Patients taking these drugs, even at therapeutic doses, for two or more months, may develop a physical withdrawal syndrome. The cardinal feature of the syndrome is anxiety, which may be mistakenly interpreted as a recrudescence of the original anxiety

for which the drug was prescribed." N. Hockings, B.R. Ballinger, Hypnotics and anxiolytics, in New Drugs, London: British Medical Association, 1983, 149-155.

- “Withdrawal from benzodiazepines in many cases may precipitate depression." (p108) - Priest RG, Montgomery SA. Benzodiazepines and Dependence: A College Statement. Bulletin of the Royal College of Psychiatrists 1988;12:107-109.

- “Indeed, persistence of high anxiety levels beyond 28 days post-withdrawal is usually interpreted not as a withdrawal effect, but as re-emergence of an underlying anxiety state previously controlled by the benzodiazepine (14,15) and often results in reinstatement of benzodiazepine treatment...Persistence or worsening of anxiety after withdrawal does not necessarily imply the re-emergence of an anxiety state existing before withdrawal. Indeed, some patients experience major panic attacks and agoraphobia for the first time after withdrawal.” Protracted Withdrawal Symptoms from Benzodiazepines Published in Comprehensive Handbook of Drug & Alcohol Addiction 2004 Professor C Heather Ashton, DM, FRCP

The department will not introduce a universal benzodiazepine withdrawal protocol, nor will it take effective measures to prevent addiction occurring in the first place. And yet the prison service does have a protocol for withdrawal. And it is mandatory. If not followed, prisoners can sue the authorities. How does the department defend its absence in the NHS where patients have no legal redress?

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CLINICAL SERVICES FOR SUBSTANCE MISUSERS
CHECKLIST TO SUPPORT DELIVERY OF MANDATORY ACTION STANDARD

Effective clinical management of substance misusers will be delivered by evidence based services which:

- identify, assess and treat substance misusers in line with the Department of Health guidelines (1999);
- contribute to throughcare plans;
- provide information on high risk behaviour, harm minimisation and secondary prevention to patients and refer to CARATs drug workers as appropriate.

KEY AUDIT BASELINES

To be audited by Prison Service Standards Audit Unit.

Governing Governors must ensure that there is a written and observed policy statement on the establishment's substance misuse service which includes:

- the clinical services provided by health care;*
- guidelines for opiate, alcohol and benzodiazepines detoxification;*
- information on assessment, treatment setting, essential observations and treatment of overdosage, in line with Department of Health guidelines (1999); *
- evidence of health care involvement with CARATs care plans; evidence of NHS specialist involvement in preparation of guidelines; evidence of regular contact with NHS substance misuse specialist services; urine sample taken for testing for opiates, stimulants and

benzodiazepines prior to starting detoxification programme and result placed in Inmate Medical Record (IMR);

- guidelines for the management of pregnant women prepared jointly with NHS obstetrician and substance misuse specialist.

Note : * are key audit baselines in the Prison Service Standard Health Services for Prisoners, the other baselines will be added to the Health Services for Prisoners Standard when it is next revised.

THE FOLLOWING CHECKLIST SETS OUT IN DETAIL THE STEPS THAT **MUST BE FOLLOWED TO DELIVER THE MANDATORY ACTION**

THE CLINICAL SERVICE

MANDATORY ACTIONS	MANDATORY TASK LIST
Identification To identify substance misusers effectively on reception who have immediate health needs.	The initial screening of all newly received prisoners will be undertaken by a health care worker trained to identify those with immediate health needs due to substance misuse.
Staff All staff involved in the care of inmates who are substance misusers will undergo regular training and at least one will have specialist expertise.	Training needs analysis undertaken annually In Local or YOI, at least one member of nursing/health care staff to have an appropriate professional qualification in treatment of substance misusers. training to include: signs, symptoms of substance misuse and withdrawal; DH evidence based guidelines; Information on rehabilitation and therapeutic communities, including those patients who may benefit during custody, including alcohol misusers. By October 2001 at least one doctor providing drug misuse detoxification at local or YOI to undergo training to maintain a level of competence to provide assessment and management of inmates with complex needs - a specialist generalist.
Detoxification All patients to have immediate access to detoxification programmes for opiates, alcohol and benzodiazepines in line with Department of Health guidelines 1999.	Guidelines for opiate, alcohol, benzodiazepine, amphetamine, cocaine/crack withdrawal must reflect DH guidelines and include information on assessment, treatment setting, treatment guidelines, essential observations and treatment of overdosage.

Yours sincerely,

Colin Downes-Grainger
at www.benzo.org.uk