

Mrs Mary Clarke-Baker's Submissions for the Health Select Committee Inquiry: The Influence of the Pharmaceutical industry

Telephone Help-Line Counsellor/Self-Help Group for Patients of Prescribed Benzodiazepines. Voluntary Self-Help Group Sector From 1990 to 2004
Mrs M Clarke-Baker July 2004, submitted on a corporate basis.

Terms of reference used throughout:

- * Health policy
- * Professional and patient education
- * Prescribing practice and patient use

PATIENTS WITH PRESCRIBED BENZODIAZEPINE ADDICTION ILLNESS AND THEIR INABILITY TO ACCESS PROPER HEALTH CARE WITHIN THE NHS

1 Proper health care for this large group of patients, currently one million patients, does not exist within the NHS, no provision of health care whatsoever for decades and up to the present date; as a consequence patients have been stigmatised openly as 'not deserving' treatment, for treatment is refused by exclusion. Consequently, this particular group of ill patients are purposely denied their basic human rights to health care.

2 With no Government stamp of approval for the provision of proper treatment for these patients, (no services yet set in place, no doctors yet trained in benzo addiction illness) means no treatment whatsoever for patients, so no respect.

3 In this unhealthy climate, of patient exclusion, 'rogue' doctors have had a free hand to treat patients as they see fit, for no-one is accountable or 'seen' to be accountable for patients who are 'outcasts' within society. With no provision of health care for stigmatised patients, it follows that doctors/others can also drop their standards of respect and their duty of care through treatment, through attitude, through stern authority, and without moral obligation and integrity. Patients are valued no more, for no demands have been made of doctors/others to actually provide the proper care and treatment for 'their' stigmatised patients, and so thousands of patients have suffered horrendous treatment, patients health has deteriorated as a result, and this continues up to the present date. (see enclosures, case histories).

PRISONERS RIGHTS ARE RESPECTED, 'PROPER' TREATMENT FOR DRUG ADDICTION, PRISONERS HAVE 'A CARE PLAN'

4 Clearly, there are 'two' standards of health care in the UK - exclusion and acceptance, with Government approval. Prisoners have a Care Package for drug addiction illness, so prisoners have a CARE PLAN, to include e.g. Good Practice Management, Information and Education on Drugs, (to include benzodiazepines) Assessment, Counselling, Referral, Advice and Throughcare Services, Rehabilitation, Therapeutic Sessions, Drug Workers, Drug Specialists, Local NHS Drug Services, Improve prisoners self esteem, Assisting successful reintegration into

the community, and rightly so. Any prisoner who is suicidal to have someone watch over them for the prevention of self harm.

5 Excluded benzo patients, who live within the community, who are desperate for proper treatment and care, seemingly, do not 'deserve' and therefore do not receive, as 'outcasts', the specialist treatment and CARE PLAN that prisoners do receive, which is specifically tailored to meet prisoners needs, and so, the people who are excluded, and I include myself, are asking why?

Contents

- Introduction of myself, the voluntary work that I do, plus my Disability.
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- First case history (anonymous)
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INTRODUCTION

Personal History

I have worked within the voluntary self-help group sector since 1990, as a telephone help-line counsellor for patients who are involuntarily addicted to prescribed benzodiazepines. I set up a self-help group locally in 1990 and received funding from Leicestershire Health for five years, until funding was stopped. Funding enabled me to visit patients in the City and far reaching villages, who were far too ill to travel to the group.

In latter years I have researched the damage caused by long-term addiction, with the help of the many case histories taken from patients withdrawing from benzos. I also follow treatment through, helping and supporting patients through their protracted rehabilitation and I note their progress, I also note their disabilities as drug related

and permanent. Patients have fits and strokes during unmonitored drug withdrawal, so I monitored patients, and their treatment by doctors.

Similarly, I came off benzos in 1985 after long-term addiction to prescribed diazepam, of eleven years. My severe drug withdrawal was not monitored, during which time I suffered a stroke, and I have memory loss for most years of my life, so I lost much learning, which went unnoticed by doctors, hence no treatment whatsoever. The result of which I now have brain damage, memory problems, 'acquired dyslexia', predominantly visual, a cognitive impairment, ME, a blood disorder and fibromyalgia, tinnitus, severe head pain, and movement in my head. I am still in self help rehabilitation of relearning grammar, spelling, cooking and many other things.

FAIR TREATMENT FOR ALL PATIENTS

THREE ANONYMOUS CASE HISTORY'S FROM MY CASE NOTES

~This paper details the appalling, degrading and inhuman treatment that patients receive on the NHS within the Community/ home setting

FIRST CASE HISTORY CASE HISTORY FROM 2003-2004

Ms X. Age 64, lives alone, has recently become addicted to a benzodiazepine for the 'second' time in her life, understandably, Ms X is angry and is totally traumatised that prescribed drug addiction has happened to her twice.

Brief case history.

In 1964 Ms X was prescribed Librium, then diazepam, she became addicted and took diazepam for 23 years. Realising, eventually, that she was addicted she approached her GP to come off diazepam. With the help of her GP she gradually come off diazepam over a three year time scale in 1988, a horrendous experience. Notably. Ms X is now very wary and questions the action of any drug prescribed, as she would never take another addictive drug, for obvious reasons.

Recently in May 2003, Ms X approached her GP for help with slight anxiety, and 2mg of Clonazepam was suggested by the GP. (2 mg of clonazepam is equal to 40 mgs of diazepam)

Ms X asked her GP if clonazepam was addictive. The GP assured Ms X that clonazepam was not addictive. Ms X was reassured and 2mg of clonazepam was

prescribed. After several months of taking clonazepam Ms X was feeling very ill, so she returned to the doctor. The doctor said she would reduce the drug by 1 mg. (the loss of 1mg is equal to losing 20mg of diazepam per day, a far too drastic and dangerous reduction in daily dosage.)

Ms X returned home and became very ill, so ill that she had a fit. This is confirmed by a close friend who was with Ms X that day, who was very worried about what was happening. From here the family took it in turns to stay overnight to care for Ms X, for she was very frightened and a very ill lady, who cannot look after herself anymore due to severe withdrawal symptoms. The family have had to become her carers. They bring her meals in, they do the shopping, cooking and cleaning. The family are very worried and they have become extremely tired.

A Community Psychiatric Nurse made two visits to Ms X, never to return due to illness. During this time Ms X is changed over to diazepam and continues to reduce diazepam as outlined by the CPN. Ms X is now on her own, as the CPN is not replaced. No action for continuing treatment for Ms X or her care is initiated either by the GP or the CPN. No interest has been shown. If Ms X wants to be monitored she will have to visit her doctor but she is far too ill to travel. A friend offers to take her and with immense effort Ms X arrives at the surgery. During the appointment the doctor tells Ms X to get a bus to the Drug Dependency Unit in Leicester. Ms X wants to talk about her symptoms and other health problems but the doctor states that she is now 'out of time'. Call back again, is the response.

A friend recommends Ms X to telephone me, hence the introduction in February 2004. Ms X is now aware that clonazepam is addictive, and is now down to 18mg of diazepam per day and is a very ill lady, she is handicapped both physically and mentally with severe withdrawal symptoms, she is also an intelligent lady who is traumatised by what has happened to her. The recommendations I made were to stop reducing the drug until we can get a perspective on which way to go, for Ms X had suddenly lost one and a half stone in weight, such a big weight loss meant that any drug stored in the fat cells had also been lost, hence her severe withdrawal symptoms.

An emergency doctor was called one evening by Ms X's daughter. The doctor examined Ms X and wrote a lengthy letter for her GP, saying, you need to have your heart monitored, give this letter to your doctor. The letter was delivered by hand to the surgery but has now gone missing and. even though the family keep insisting that Ms X needs to have her heart monitored, the reply is this, "we can't find the letter", and so Ms X is still waiting for heart monitoring months down the line.

Ms X telephones the Drug Helpline in Leicester. They are shocked to hear of her harrowing withdrawal experience, and of receiving no help or treatment for her drug withdrawal, but they do not visit people at home. However, because Ms X is very ill, they visit Ms X. The outcome of these home visits are, "You need to be assessed, you are not receiving the help you need."

Ms X is recently assessed by Social Services, who offered one hours shopping for five pounds, and a difficult form filling exercise for Ms X, who cannot get her head round filling forms in anymore. Ms X's memory is now very poor, her writing and

spelling have deteriorated as well. Being unable to cook or clean house Ms X now pays for someone to clean house for her, out of her state pension, to relieve the family of this burden.

The family, as carers, are exhausted and are now suffering from symptoms of stress. One family friend, (previously of good health) who stayed long weekends to care for Ms X, has recently had three heart attacks and is very ill, which is most probably due to the ongoing stress involved in looking after someone who is very ill, namely Ms X. The family is crumbling and so is Ms X, who will not recover until she is off diazepam completely, which could take a further one or two years and longer. The protracted 'post' withdrawal syndrome, which is well documented to occur with many patients, could lengthen Ms X's illness for many more years to come. Also, a friendly neighbour, who had helped Ms X recently has also become ill and can help no more. Relatives and friends have been tested to the limit, as more of them have had to become carers, and have succumbed to the symptoms of stress overload, for holding down a job and being a carer at the same time is very stressful indeed.

Ms X has had a back injury/disability for many years now but due to drug withdrawal causing muscle weakness, this has exacerbated her back problem. She now has sciatic pain as well as a worsening back problem coupled with severe withdrawal symptoms.

It is now July 2004. Ms X has been informed that there are no CPN's available to visit her, no Psychotherapist and no drug Counsellor either. There is also no help for Ms X within the home either, for shopping, cooking, cleaning or for her safety when bathing.

Ms X has had enough, she is very ill, is traumatised, has reactive depression and is feeling suicidal, stating, these drugs have taken my life away, it is not my fault that I am ill, and I just can't cope anymore. The fact that Ms X has not received treatment on the NHS, (many patients are refused treatment) has only served to make her more ill. She is desperate for help but is now resigned to her fate of receiving no health care whatsoever, saying, I give up, I can't cope with this anymore.

For three months, since March of this year I have tried to organise care and treatment for Ms X, (as have family and friends) but all inquiries, and there have been many, have come to nought. Only recently, by demanding that Ms X most definitely needs a Physiotherapist to visit her at home, has Ms X received treatment from a Physiotherapist for her worsening back problem.

More recently, Ms X's family requested a meeting with the doctor at home, to ascertain what help is available for Ms X. During this tense meeting, and with regard to Ms X speaking about her illness and her trauma, the doctor said to Ms X, with attitude, "forget about the past and look to the future". An unsuccessful meeting, the result of which has traumatised the patient even more, for no treatment was discussed or even alluded to by the doctor.

No Care Plan, no information on drugs, no physical assessment, no advice, no support, no counselling, no rehabilitation and no through care, no monitoring on a regular basis, no help within the home.

SECOND CASE HISTORY

This patient was withdrawn from benzos far too quickly and drastically, has been bedridden for many years now, is permanently disabled and she continues to deteriorate year by year. In my opinion, this lady is dying for lack of proper treatment.

CASE HISTORY FROM 1993-2004 WORST CASE SCENARIO

Mrs X. Age 50, is married. Past case history. Prior to taking diazepam she was physically and mentally well. Benzos were prescribed for slight anxiety, valium/diazepam 50mg per day. However, this lady worked full time all during the 26 years of taking 50mg of diazepam per day. She did not notice any physical or mental side-effects. She said she functioned well on the drug, as many people do, if on a lower par, which she would not notice herself.

1991. A new GP to the practice, on looking in her file, asked if she would like to come off diazepam. Being totally ignorant about the drug that she was taking i.e. addiction, withdrawal symptoms, tolerance/adverse effects, she replied, "I had never thought about stopping the drug before, but why not". She was referred to a Psychologist where she listened to relaxation tapes and talked. (no mention of withdrawal symptoms, no advice of what might happen when reducing diazepam) He referred her to a Psychiatrist who would treat her for coming off diazepam. Her husband was also ignorant about diazepam and drug addiction.

Mrs X was told by the psychiatrist that she would be off valium in 6 months. (a far too drastic withdrawal regime for any long-term benzo patient). Firstly, she was reduced by 5mg on every visit, not forgetting that Mrs X knows nothing about withdrawal symptoms, and nothing is explained to her by the psychiatrist, no information whatsoever about diazepam or withdrawal symptoms. Mrs X said to me, "It was okay at the beginning, I thought I was doing quite well, but then I felt quite ill, I could not concentrate at work and I had difficulty driving to work. Everything seemed to be going wrong. I would drop things and I become disorientated, I would get confused and I had never made mistakes at work before. I found it difficult to cook the evening meal. My life was crumbling around me. I, myself, was crumbling, physically and mentally."

A few months later, Mrs X was down to 12 mg and had become very ill. She said to the psychiatrist that she could not reduce further because she could not function as before, and could he put her in touch with anyone she could relate to concerning these drugs. He replied, no. Mrs X asked if her husband could attend the sessions with her, (her husband was very worried by his wife's sudden illness) answer, no. At a later date Mrs X wanted to include the family, she wanted them to know and to understand her illness. The psychiatrist replied, there is no need to inform the family. On another visit to the psychiatrist, when feeling very ill, he shouted at Mrs X, "***I want you on Antidepressants! I just want to get you off that crap!***"

Mrs X said, she recoiled from such behaviour and language. Mrs X is far too ill to work now, so she gives in her notice at work and forfeits her work pension,

(unknowingly) which she would have received if she had been retired on the grounds of ill health.

She said, each session was the same, in that the psychiatrist never used her name but would just greet her with, "Well?". He never used her name during any session. Mrs X said, she asked a lot of questions but most were blatantly ignored and were returned with a silent stare or a mumble. She said to the psychiatrist, "I just cannot reduce anymore", so the psychiatrist resumed her dose back up to 50mg. Mrs X says it has been terrible these past two years and the family now know what is happening, but they do not understand why she is so ill. Mrs X said, "My life is broken, my husband is a very worried and a very stressed man, I cannot go out anymore, I am far too ill."

I advised Mrs X to have her husband sit in at all sessions with the psychiatrist. He did. Mrs X told me, the psychiatrist was totally different in his attitude when her husband was with her. And as instructed (my advice to them) they both asked many questions, for they have now read information on benzodiazepines and withdrawal symptoms. Eventually the psychiatrist admitted that she had been "**brought off drugs far too quickly and drastically.**"

Three years later Mrs X is still taking 50mg of diazepam per day and is physically deteriorating and now has another psychiatrist, who sets his stop watch for one hour, and if by chance Mrs X is speaking when the clock chimes, the psychiatrist puts up his hand to stop her talking, meaning, no more time, so Mrs X's mid-stream sentence remained mid-stream. On my asking Mrs X about the outcome of these sessions, and what does the psychiatrist say about her illness and prognosis, her reply is, "**The psychiatrist said that he didn't think she would ever get better.**" Her husband heard this statement as well.

COMMENT What is disturbing here is that tranquillisers are never mentioned, (common practice) either by her psychiatrist or her GP. Mrs X's severe illness is not explained to her. She said, "It is as if my doctor does not recognise this illness."

How strange, that this patient, who was receiving ongoing treatment for drug addiction, who was coming off benzos, who is now very ill, who has been told that she will never recover, who is still deteriorating, and yet benzos are never mentioned or even alluded to. Notably, the psychiatrist does not explain her 'illness', withdrawal symptoms are not discussed, it is as if the drug has no connection whatsoever with this patient's severe illness.

At a later date: Many of Mrs X's disturbing withdrawal symptoms have now been put down to a 'virus', a virus that just will not go away, in fact, this so-called virus has been used as an excuse for 6 years and more, her symptoms are explained by 'silence'. How can a very ill patient such as Mrs X, who has been under the care and treatment of several doctors, become so disabled and is now bedridden, slip invisibly through the system of the NHS, with no monitoring by her GP and no monitoring by the psychiatrists. Easy. Patient health care is totally ignored.

2002. Mrs X said, "I know I am deteriorating." Her husband confirmed the same to me. Mrs X is now permanently in bed and permanently disabled, all muscles have

atrophied. Her very caring husband, many years ago, had to sacrifice his career and is now her main and only carer. These people are now totally 'isolated' in their own pain with constant worry and the ongoing stress of just coping and surviving from day to day. Mrs X falls often when trying to get to the bathroom, she cannot pull herself up. She now leaves the bathroom door open in case she falls again, and is trapped behind the door again.

Recently, and far too late by many years, Mrs X has a physiotherapist visit at home for the past 5 weeks, who will not even allow her to walk unaided, who said to Mrs X, when a hospital appointment had come through, you could not possibly get to the hospital by car or make the journey by ambulance and if you did you would be far too ill on arrival to have treatment. (Not verbatim but Mrs X's account to me). Alas, the physiotherapist had to be cancelled due to Mrs X's weakened state and excruciating pain during treatment, treatment that had come far too late for this seriously ill patient.

Months later: September 2002. Mrs X says that she hasn't seen her GP for nearly 2 years now. Her husband makes an appointment in her name, a telephone appointment.. All the GP keeps saying, over and over again is that she has got to get out of bed. The GP will not visit her.

Six weeks ago, when Mrs X was having worsening health problems, her husband telephoned the GP surgery, who sent out a locum doctor, who organised blood tests. The blood tests came back with markers. The GP will not discuss the results of these tests with Mrs X's husband so Mrs X spoke with the GP on the telephone. She said, he shouted at her, "You come and see me and I will tell you the results! It is a minor abnormality with your liver." She said, "You realise that I will worry about this and it will make me more ill." He replied, "Yes". Mrs X said to me, "He was bullying me, he was shouting at me."

She also said to the GP, why blood tests now and not twelve years ago? Silence ensued. She said, her husband gets so down, he just sits in the chair in the bedroom with her. I then spoke with her husband who said, "I think this is a carrot to get her out of bed to the surgery, but she is far too ill. He said, "She is bedridden and she is deteriorating."

2004, speaking with Mrs X recently. She says, very slowly, as if her voice is fading away, "I am much worse, I feel sick all the time, my back is worse, my bowels do not work" and, eventually, after a long silence of waiting for her to speak, she said, very slowly due to her weakness, "Thank- you -so- much- for- calling- me." This lady's memory is so poor that I have to explain things to her husband as well, for she cannot remember the information that I convey to her.

When I visited Mr and Mrs X approximately 10 years ago, she was in bed and had black rings under her eyes, she was pale and very ill, and since that time. after being withdrawn from diazepam far too quickly and drastically, she has become an invisible person with an invisible illness, who is in receipt of high rate disability living allowance and carer's allowance for many years now.

No Care Plan, no information on drugs, no physical assessment, no monitoring, no advice, no support, no counselling, no treatment and no through care, no help within the home

THIRD CASE HISTORY FROM 1995-2004 A VERY SAD CASE

This senior citizen has been 'involuntarily' withdrawn from benzodiazepines by her GP, she was addicted to benzos and had taken benzos for over 30 years.

Miss X, age 67, lives alone. Prior to taking benzos she was physically and mentally well. Librium/ Chlordiazepoxide was prescribed for pre-menstrual tension many years ago. She said she worked and functioned quite well on the drug, until she was taken off them and suffered cold turkey in hospital many years ago, the experience of which she describes as a "nightmare never to be forgotten". Benzos were reinstated because Miss X was very ill and could not function on a daily basis, she has been unable to work since coming off cold turkey many years ago. Miss X has taken prescribed benzos for 30 years.

She said, last year in 1995, her GP - and this came from out of the blue - said to her, with his finger pointing, "3, 2, 1, then off!" He said this with authority. She said, she felt intimidated and humiliated. She knew what he meant but was too frightened to say anything to him. He said, "Government says to get people off these drugs and this is what happens." She said, "He seemed to delight in doing this to me". She said, "I wasn't asked if I wanted to come off the drug " and "We are taken off these drugs so cruelly." This lady has no choice but to come off the drug. Her life is a nightmare and she lives in constant fear. A quiet, polite, unassuming, intelligent lady who lives alone.

A friendly pharmacist, (she confides in him) advised her not to come off the drug but to stay on it, as she had been on it for over 30 years. He explained to her, that her body had got used to the drug. Do not come off it, he advised. She said, "The pharmacist put his arm round me. I think he felt sorry for me."

This lady is desperate. She said she has been very ill for the past nine months and she doesn't want to feel ill anymore. "I want to feel well." Miss X stresses and she reiterates to me that she is feeling very ill and she just cannot carry on like this anymore. The doctor just gives me less pills and I have no choice. She said, the doctor implies that I will get off them - but he does not actually say so, he just prescribes less pills. She says, "there is no directive", meaning no advice on how to reduce the drug properly. Miss X desperately wants someone to support her, to go with her to the doctor. She said, she is very frightened. Miss X's experience is not unusual. She is being involuntarily withdrawn from the drug.

Miss X's appointment with the doctor: when suffering from withdrawal symptoms e.g. loss of balance, headaches, blurred vision, feeling sick, diarrhoea, many flashbacks, near to collapsing, legs buckle beneath her, is sleeping down stairs due to loss of balance and unsteadiness of being pulled to one side, (too many symptoms to relate here) and after telling her Doctor about these symptoms, he said

to her, "Have you been drinking?" She said, "I felt insulted." And indeed she had been insulted. This lady writes to me and I telephone her to see how she is faring. She keeps in touch by letter and the occasional telephone call.

2002. Miss X is off benzos completely, she has severe withdrawal symptoms.

In July 2004 this lady still has many 'post' withdrawal symptoms, her health is poor and she is depressed. She says, "I have not recovered physically or mentally from this horrendous experience." Patient now aged 76.

No Care Plan, no information on drugs, no physical assessment, no monitoring, no advice, no support, no counselling, no rehabilitation and no through care, no help within the home.

HM PRISON SERVICE ORDERS

Order Ref. no. 3550

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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 overdose, 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.

Issue Number 116

Issued 20/12/00

CHECKLIST

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

1. THE CLINICAL SERVICE

MANDATORY ACTIONS	MANDATORY TASK LIST
<p>Identification</p> <p>To identify substance misusers effectively on reception who have immediate health needs.</p>	<p>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.</p>
<p>Staff</p> <p>All staff involved in the care of inmates who are substance misusers will undergo regular training and at least one will have specialist expertise.</p>	<p>Training needs analysis undertaken annually</p> <p>In Local or YOI, at least one member of nursing/health care staff to have an appropriate professional qualification in treatment of substance misusers.</p> <p>training to include:</p> <ul style="list-style-type: none"> 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. <p>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.</p>
<p>Detoxification</p> <p>All patients to have immediate access to detoxification programmes for opiates, alcohol and benzodiazepines in line with Department of Health guidelines 1999.</p>	<p>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 overdose.</p>

4. MANAGEMENT OF BENZODIAZEPINE MISUSERS

Objective

To provide clinically appropriate service for the withdrawal of benzodiazepine in those who are dependent.

MANDATORY ACTIONS	MANDATORY TASK LIST
Each prison will have a service for management of benzodiazepine withdrawal for those who are dependent.	Guidelines for the management of withdrawal of benzodiazepines to be prepared in conjunction with local NHS Substance Misuse specialist in line with DH guidelines (1999) to include: <ul style="list-style-type: none"> identification on reception and clinical assessment including, signs and symptoms of benzodiazepine withdrawal the need to obtain information from community services confirmatory urine test management guidelines, in line with those recommended by NHS

Issue Number 116

Issued 20/12/00

RECOMMENDATIONS FOR GOVERNMENT (M. Baker Submission)

To provide proper health care and treatment for all benzo patients, similar to the health care package that prisoners receive in HM prisons. e.g. CARE PLAN, Drug information and Education, Counselling, Assessment, Referral, Advice and Through care services, Rehabilitation. Benzodiazepine Specialists, To ensure a coordinated service is delivered across all care sectors.

CARE PLANS should be 'mandatory' for all patients who are willing to withdraw from benzos and/or those trying to reduce but not to cease taking their drugs. e.g. the elderly, disabled, or any patient who 'physically' or 'psychologically' cannot withdraw completely, as many patients cannot.

- * Patient CONSENT must be obtained, prior to drug withdrawal
- * Patient consent can also be WITHDRAWN at any time
- * Patients require benzo clinics 'specifically' for their needs, as residential facilities for treatment, education and rehabilitation with respite care facilities, ideally

large houses in a countryside setting, and specialists with expertise who are knowledgeable in benzodiazepine addiction illness/ withdrawal to attend to their needs. Many patients can withdraw within their own home setting but need to have these services as an integral part of treatment, as firstly, it takes several years to withdraw from benzos. Secondly, patient rehabilitation can only begin when the patient is off the drugs and is well enough to start rehabilitation. This is subject to patient health status and patient need.

* TOTALLY INAPPROPRIATE TREATMENT e.g. Psychiatric units/ alcohol and illicit drug services, where many benzo patients have been forced to suffer a far too drastic drug withdrawal, which has culminated in permanent damage, physical, mental, and psychological, due to the lack of education and understanding by attending doctors and nurses, many of whom have been unwilling, for many years now, to learn from patients suffering of unbearable withdrawal symptoms, due to a too fast withdrawal regime, most patients being told "it's all in your mind" and "shut up" when patients are screaming and crying in agony of excruciating pain and, when patients try to explain their illness, who become verbally aggressive, when their illness is dismissed as not excising, the doctor threatens, and states with authority, "If you do not behave I will have you sectioned." (comments from patients/ my case notes)

* Plus, the totally 'inappropriate' prescribing of addictive sleeping pills to these same patients, who are sent home very ill, from the psychiatric unit, now off their original benzos, but still addicted to the 'sleeping drugs', is treatment by uneducated ignorance, one assumes, so patients continue to treat themselves at home, with the help of experts within the voluntary sector, to wean off sleeping drugs, if they are lucky enough to know the telephone number or that help does exist, which many people do not, and so their benzo sleeping drug is continued to be prescribed by the GP, thus perpetuating drug addiction illness for the patient.

* Benzo patients should not be coerced or be threatened with being sectioned, as this precipitates vulnerable patients to 'take their own life' successfully, and patients should not have to take their own life for 'fear of being locked up' when they are seriously ill, due to the inability of doctors to provide proper caring treatment for patients who can clearly be seen to be suffering from severe withdrawal symptoms and trauma.

* To stop patient abuse. Doctors who choose to ignore Government Guidelines to be accountable. e.g. when a patient's benzodiazepines are stopped abruptly by the doctor and therefore, the patient has no choice but to suffer cold turkey, this barbaric treatment should be classed as negligence with intent. Likewise, for the patients who are 'involuntarily' withdrawn from the benzodiazepines e.g. ad-hoc prescribing of less tablets per month, for many years, with no advice or support. Clearly the intent to harm, physically, mentally, and psychologically is achieved, and is with out doubt negligence with intent.

* Government Guidelines should strictly address patient safety, of 'rogue' and uneducated doctors causing harm to patients, to make CARE PLANS 'mandatory' for all benzo patients - thus accountability for proper treatment and patient care is

assured, hence the professional doctors who have integrity, who do care and help their benzo patients will be protected.

* Interested professionals to receive training in benzodiazepine drug addiction illness. Patients, now off benzos for many years, know all aspects of benzo addiction illness, so their experience and their expertise would be invaluable for professionals in training.

* Prescriptions for benzodiazepines should require the signature of two doctors, hence accountability, this will help to protect doctors and vulnerable patients. Free prescriptions for patients who are addicted to benzos long-term, bill the pharmaceutical companies, for patients are more than insulted in having to pay for drugs for their involuntary drug addiction and no proper treatment to boot, so patients have no choice but to pay for prescriptions drugs that they really do not want to 'have' to take.

* Pharmacists to supply leaflet information on benzodiazepines with all benzo prescriptions.

* Benzodiazepine leaflets available and displayed in all GP surgeries/hospitals/chemists.

FURTHER POINTS

PATIENTS AND RELATIVES ARE TOO FRIGHTENED TO COMPLAIN

Many ill patients suffering from 'drug tolerance' illness, and those who are withdrawing from benzos, are far too frightened to complain to their doctor, and relatives are frightened as well and for good reason e.g. the patient's drug could be stopped abruptly, and drugs are suddenly stopped by doctors, so the patient has no choice but to suffer 'cold turkey', or the doctor prescribes 'fewer' tablets per month, hence the patient is 'involuntarily' withdrawn from drugs, without help or advice, or the patient and the complaining family are taken off the doctors list.

These are the dire consequences that many patients suffer from if they or their family dare to complain about 'treatment' or 'lack of treatment'. For these reasons, patients and their relatives do not complain, they dare not make 'waves' for fear of the result, they are too frightened to do so.

For all the above reasons, I cannot help many desperate patients, as I need to have their consent before I can act on their behalf with their doctor. In all cases consent is refused. Patients confide to me, and say, that if I make 'waves' with their doctor their drugs will be stopped, for their doctor will be very angry. Alas, patients know, by experience, of just how ill they become if they forget to take 'one' tablet, but to lose all their tablets is unthinkable to them.

PATIENTS JUSTIFICATION FOR COMMITTING SUICIDE

Just the thought of having to go 'cold turkey' is enough to precipitate these vulnerable patients to commit suicide, for the result of having to go benzodiazepine cold turkey is known to disable people for life, (word gets around of those who have been taken off their drugs). Indeed many people are disabled after experiencing cold turkey, even those who worked full time, when taking the drug, and who want to resume their career, never work again. Also, the patients who are threatened with being sectioned do take their own life, I have personal experience of this happening with a patient that I had known and helped for several years, who was trying to get help with a psychiatrist in the area where she lived, who ignored her illness, and with attitude threatened her with being sectioned. Her death is an experience that I will never forget.

So there are many issues. However, I do know for sure, that if I can treat patients successfully over the telephone, and lead them through to a drug free life, for which these people are so very grateful, that if 'interested' professionals had training in benzo drug addiction illness, they could also offer proper treatment and care.

MANY BENEFICIAL CHANGES IN PATIENTS OFF BENZOS/ IN REHABILITATION

This is always my reward, it is an exciting time for a benzo expert every time, for many patients literally feel 'reborn'. Most say it is absolutely wonderful to get my brain back, my thinking has changed; my thinking has expanded, I am now 'creative'. They actually become 'aware' of their surroundings, they begin to read books and newspapers, they take an interest in what is happening in the outside world, depression looms no more, all positive changes for the better, their quality of life and that of their family is restored, even though many people remain ill, to different degrees, the fact that they have got their 'brain back, that thinking is restored, is a bonus to that person every day!

PATIENTS CONDEMNED TO LIFE-LONG ADDICTION

To deny these patients treatment is to condemn them to live in a small, 'unnoticed' and dull world, unfeeling, unemotional, depressed, suicidal, unthinking, panic stricken drug induced state, and forgetting on a daily basis for the rest of their lives, never knowing that they have lost their brain because many patients are too drugged to even think about their brain or that they do have a brain, such are the effects of benzos on patients, their cognitive impairment or 'non- thinking' state.

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