The Patient is always Right?

Colin Downes-Grainger

August 21, 2009

- In the UK people are now so full of themselves that they ignorantly argue with experts .....the public do not recognise they are not omniscient and professionals are derided day after day. A quarter of consulting time is spent arguing with idiots who think they know better...

- The patient's views and treatment wishes over-ride any notion of whether it makes sense or not.

- There is no facility on the NHS complaints system to tell a patient that they are a manipulative, obnoxious, psychopathic liar and a troublemaker. No, the patient is now always right and has to be appeased and the healthworkers have to be sent on communication skills courses to be re-educated.

- It is time the NHS started charging neurotics for plaguing the NHS with their incessant self-obsessed and greedy concerns.

A GP Comment on an Independent article re NHS failings 21.8.09

Perhaps there is a certain percentage of what are commonly known as the 'worried well', and I have no doubt that a proportion of wrong-headed or obnoxious individuals will pay visits to the surgery occasionally but the views expressed are all too typical of a major attitude in medicine, applied universally – *me expert, you listen.*

The benzodiazepine story shows more clearly and with more evidence than anything else, the power of those who run health provision to ignore the suffering of large numbers of people – a condition which they allowed to happen and then egregiously ignored. To protect themselves and maintain the system, they have permitted the ongoing injury of individuals who otherwise would have lived the lives of normal human beings. And as Phil Woolas MP, a government minister in 2009, said in 2000:

> "The scale of the [benzodiazepine] problem is so large...that it is beyond the grasp of many politicians and people in power to solve it. I think there's a paradox here, because you have this huge problem with a huge number of people involved, and yet we seem as a society to be incapable of acting on it. We can only cope with problems that are so big...we can't cope with this one."

And it is necessary to wonder why.

Anna Higgitt who later went on to become 'senior benzodiazepine adviser' at the Department of Health said this in 1985:

> "Withdrawal symptoms have been reported after treatment for as little as four to six weeks. The withdrawal symptoms observed are wide ranging, and, while they include some related to anxiety, they are clearly distinguishable from a simple re-emergence of pre-existing anxiety. Particularly frequently reported are instances of increased sensory perception such as hyperacusis, photofobia, paraesthesia, hyperosmia, and hypersensitivity to touch and pain, but gastrointestinal disturbances, headaches, muscle spasms, vertigo, and sleep disturbances are also frequent.
>
> The proportion of long term users of benzodiazepines in whom withdrawal symptoms may be expected to emerge has been variably estimated to be between

15% and 44%. The symptoms typically emerge in the first week after stopping the drug but may develop after a reduction in dosage. Until recently the withdrawal syndrome was reported as lasting for up to three months, but we are now seeing more patients whose symptoms have persisted for more than six months - in some cases for a year or more." [p.688]
Higgitt AC, Lader MH, Fonagy P.
Clinical Management of Benzodiazepine Dependence.
BMJ 1985; 291: 688-690.

And yet in spite of this expert insight and the role she is said to occupy, today the Department of Health more or less agrees openly with a view that patients addicted to benzodiazepines by doctors are personally responsible for their condition in the same way that drug takers on the street are. Professor Ashton had this to say in a letter to health minister Rosie Winterton in January 2007:

"I have been forwarded your letter to Michael Meacher dated 14th December 2006 (Ref. P00000160942) in which you repeat your statement that "those who misuse benzodiazepines have access to a range of services both in the primary and secondary care settings to meet their needs". This is the same well-worn and inaccurate statement that you made in the letter to Beat the Benzos representatives after our meeting with you in the House of Commons in 2004, and it appeared again in a letter from Patricia Hewitt to Margaret Beckett dated 20th September 2006 (Ref. P00000139311).

You do not seem to understand or acknowledge the distinction between long-term prescribed benzodiazepine users and those who misuse or abuse the drugs recreationally, along with opiates, cocaine and other "hard drugs". The problems and needs of prescribed, benzodiazepine users were described in detail to you in our meeting in 2004. The only one of our suggested recommendations that you supported was to persuade the Chief Medical Officer to send a letter to doctors asking them to reduce their prescribing of benzodiazepines. At the meeting I personally offered to assist the CMO in drafting such a letter. This offer was ignored and his badly worded letter was a predictable disaster which resulted in many general practitioners abruptly reducing benzodiazepine prescriptions to long-term patients and some PCTs reducing their budgeting for such drugs - with similar unfortunate effects on patients.

It is a great pity that you have chosen not to keep abreast of the situation and have apparently ignored again the recommendations made in our All Party Group on Involuntary Tranquilliser Addiction meeting at the House of Commons on 7th November 2006, which was organised and attended by several MPs including Jim Dobbin, John Grogan, Jim Cousins and others, as well as many doctors with long experience of the adverse effects of prescribed benzodiazepines. including Professor Peter Tyrer and myself, and a large audience of prescribed users and other interested parties. If you were genuinely interested as Health Minister you could also have had access to my talk which reiterated the same problems as were discussed with you in 2004. I enclose a copy, which is also available on
www. benzo. org.uk

As you will see (if you read the talk) I stated again that your repeated assertions are simply not true. Prescribed benzodiazepine users do not have proper access to primary health care services because general practitioners lack the expertise and time to withdraw long-term prescribed patients from benzodiazepines, and the waiting list for psychological therapists, who are in any case not properly trained, is

up to two years in most PCTs. These prescribed patients also do not have access to secondary health care services: they are regularly refused treatment because they are not abusing opiates or other hard drugs.

Your attitude and your repeated statements lead one to despair of politicians. Like journalists they seem only interested in the subject for one moment. They may pay lip service but then turn to other matters. I understand that politics and academic medicine are worlds apart but feel that your interest in prescribed benzodiazepine users is facile and so far futile. As Health Minister the public expects more of you."

Professor Louis Appleby the DoH Director of Mental Health said this on television in 2001:

"...the treatment of benzodiazepine withdrawal in some ways is not all that complicated. You need someone to supervise the gradual reduction of the amount of the drug that you're taking and you need support and treatment for the kind of symptoms that then recur, essentially anxiety and insomnia..."
Professor Louis Appleby, BBC Tranquilliser Trap, 13 May 2001

Take a look at the side-effects listed below and after them the list of reasons for prescription leading to addiction and for some the end of worthwhile life and health. Was it worth it? Was it symptoms recurring? Was withdrawal a simple process?

List of withdrawal effects drawn up by Australian Professor Jeffrey Richards

Common Withdrawal Symptoms:

Abdominal pains and cramps
Agoraphobia
Anxiety
Breathing Difficulties
Blurred Vision
Changes in Perception
Depression
Distended Abdomen
Dizziness
Extreme Lethargy
Irritability
Lack of concentration
Lack of coordination
Loss of balance
Loss of memory
Muscular aches and pains
Nausea
Nightmares
Rapid mood changes (crying one minute and then laughing)
Fears (uncharacteristic)
Restlessness
Feelings of unreality
Severe headaches
Flu-like symptoms
Shaking
Heavy limbs
Seeing spots
Heart palpitations
Sore eyes
Hypersensitivity to light
Sweating
Indigestion

Tightness in chest
Insomnia
Tightness in the head (feeling a band around the head)

Less Common Withdrawal Symptoms:

Aching jaw
Numbness in any body part
Craving for sweet food
Outbursts of rage and aggression
Constipation
Diarrhoea
Paranoia
Depersonalisation (a feeling of not knowing who you are)
Painful scalp
Persistent, unpleasant memories
Pins and needles
Difficulty swallowing
Rapid body changes in temperature
Feelings of the ground moving
Sexual problems
Hallucinations (auditory and visual)
Skin problems
Hyperactivity
Hypersensitivity to sound
Speech difficulties
Sore mouth and tongue
Suicidal thoughts
Incontinence or frequency or urgency
Increased saliva

Rare Withdrawal Symptoms:

Blackouts
Bleeding from the nose
Burning along the spine
Craving for pills
Discharge from the breasts
Falling hair
Haemorrhoids
Hypersensitivity to touch
Rectal bleeding
Sinus pain
Seizures
Sensitive or painful teeth

Collected reasons for prescribing to patients leading to addiction

Nursing sick wife after operation
Bereavement
Emotional upsets
After an operation
Husband's accident
Socialising
Dental pain
After-flu virus
Dry eyes
Alcohol problem
Alcoholic father
Sex abuse
Stomach trouble
Hysterectomy
Business problems
Handicapped child
Shift work

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
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
Hay fever
Mother committed suicide
Vertigo
Jury service
Palpitations
Work pressure
Moving house
Loss of hearing
Cooker blew up
Claustrophobia
Illness
Post-natal depression
Back pain
Active/crying baby
Homelessness
Coach travel sickness
Cancer

Professor C.H. Ashton at Newcastle University agrees with the content of both lists and adds that tinnitus and panic attacks are also very common in withdrawal from benzodiazepines. It is not uncommon to experience many of these symptoms at the same time and/or on a revolving basis. Heather Ashton told a magazine in 2003:

> "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."
> Professor C Heather Ashton DM, FRCP, Good Housekeeping, August 2003.

Professor Malcolm Lader who worked with Anna Higgitt on tranquilliser research said this:

"It is more difficult to withdraw people from benzodiazepines than it is from heroin. It just seems that the dependency is so ingrained and the withdrawal symptoms you get are so intolerable that people have a great deal of problem coming off. The other aspect is that with heroin, usually the withdrawal is over within a week or so. With benzodiazepines, a proportion of patients go on to long term withdrawal and they have very unpleasant symptoms for month after month, and I get letters from people saying you can go on for two years or more. Some of the tranquilliser groups can document people who still have symptoms ten years after stopping." Professor Malcolm H Lader, Royal Maudesley Hospital, BBC Face The Facts, March 16, 1999.

Those in medicine with an open mind have long understood the true benzodiazepine reality and not that spun by government and its agencies. A GP wrote in 2003:

"I have started a support through withdrawal scheme for people coming off benzodiazepines. The enormous amount of suffering I see makes me wonder how much information on the toxic effects of these drugs, and illness caused by their withdrawal, reaches the doctors. The pharmacological manuals grossly understate the dangers of tolerance, dependence and withdrawal that have been demonstrated so clearly after the use of these drugs. This is not only after long-term use at high dosage, but also after very short-term use (two weeks), on a normal therapeutic dose.

We must look urgently for the most effective treatment, since a quarter of benzodiazepine users will become severely physically dependent. Widespread dependence, as much as over-prescribing, must be the reason for the enormous use of these drugs.

The withdrawal syndrome has many unique features and needs to be treated as a new disease. In acute withdrawal, psychosis, convulsions and suicides are a great deal more common than the literature would suggest. The physical symptoms, many of which are not typical of anxiety, are the worst aspect of the illness.

Some of the symptoms are belated and are not associated with the drugs by patient or doctor. Rebound insomnia is a persistent symptom. Unfortunately, and so often, doctors prescribe another benzodiazepine for night sedation when the patient complains of this. Psychological dependence is less of a problem. Many users report craving for the drugs, but at the same time feel revolted by them, and angry that they have to take them to avoid withdrawal symptoms.

Thousands of people could not possibly invent the bizarre symptoms caused by the therapeutic use of benzodiazepines and reactions to their withdrawal. Many users have to cope, not only with a frightening range of symptoms, but also with the disbelief and hostility of their doctors and families. It is not uncommon for patients to be "struck off" if they continue to complain about withdrawal symptoms. Even when doctors are concerned and understanding about the problem, they often have little knowledge of withdrawal procedure, and even less about treatment. The drugs newsletter on benzodiazepines issued in this region will help them. Is anything being done elsewhere?
Trickett S. Withdrawal from Benzodiazepines. Journal of the Royal College of General Practitioners 1983; 33: 608.

This is what the Royal College of Psychiatrists website had to say about tranquillisers in 2001:

> They are very effective at relieving anxiety, but we now know that they can be addictive after only four weeks regular use. When people try to stop taking them they may experience unpleasant withdrawal symptoms which can go on for some time. These drugs should be only used for short periods, perhaps to help during a crisis. They should not be used for longer-term treatment of anxiety. - The Royal College of Psychiatrists, July 2001.

Today, of the 8 references quoted on the same site, all 8 cite Professor David Nutt. In various lectures and papers he maintains that the drugs are not as black as they are painted and that they can be prescribed safely for extended periods of time by psychiatrists. In a lecture entitled *Brain Mechanisms and Treatments of Anxiety Disorders* at the Lundbeck Institute in November 2005 he said:

> "The (benzodiazepine) withdrawal period lasts between sort of 4 days to a couple of weeks at most I think."

Nutt is chairman of the Home Office Advisory Committee on the Misuse of Drugs. At the same time as he is saying this which flies against the great mass of contradictory scientific and patient evidence, a member of his committee Dr John Marsden was saying in a programme entitled *Britain's Deadliest Addictions*, on Channel 4 in November 2007:

> "If any drug over time is going to just rob you of your identity and be an ironic reaction to early effectiveness.[sic] To long, long term disaster, it has to be benzodiazepines."

The stone marker for Sir Christopher Wren in St Paul's Cathedral reads:

> Subtus conditur Hujus Ecclesias et Urbis Conditor, CHRISTOPHERUS WREN; Qui vixit annos ultra nonaginta, Non sibi, sed bono publico. Lector, si monumentum requiris, Circumspice. Obiit 25 Feb. MDCCXXIII., aetat. XCI.
>
> "Underneath lies buried Christopher Wren, the builder of this church and city; who lived beyond the age of ninety years, not for himself, but for the public good.--Reader, if you seek his monument, look around you.--He died on the 25th of February, 1723, aged 91."

No member of government, no pharmaceutical company executive or drug's regulator will ever merit such a marker. If a marker were to be erected outside any corporate office or government building it would read something like:

> In this place and others we sold out the public good for personal or financial gain and the maintenance of hubris. Rest in Peace all those we failed and exploited.

Colin Downes-Grainger
21 August 2009