

THE STORY OF A 30 YEAR ADDICTION TO BENZOS

by Colin Downes-Grainger

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From childhood I was introspective and not confident, and I was a perfectionist by nature. Neither was I particularly adept at social skills. Teacher training college in London in the late 60's, after doing A Levels by correspondence course, was the happiest time of my life, when I was self-regulating. Because the medical establishment swallowed uncritically the sales pitch of the drugs companies, then from the moment I went to a doctor in London about my inability to relax, I was on the road to medical harm. The doctor gave me a course of valium.

When we moved back to the north-east for my first teaching job I had occasional prescriptions for valium, followed in due course by repeat prescriptions. I did not have a medical problem. I was just in the wrong type of job and in the worst possible type of school – open-plan and team teaching – for someone with my personality, although I was very successful there. As I would use up the prescriptions early each month, and could no longer relax, I eventually added alcohol in an attempt to achieve mental ease. I had never been a drinker before. I can see now that the stress I increasingly felt was greatly complicated and magnified by the repeated periods of physical and mental withdrawal from valium that I went through each month.

I had achieved a lot from humble beginnings. I was a viable human being before I became addicted. I had always worked and solved my life's problems in one way or another. I had a wife and family and I would probably have matured and mellowed naturally. Only at the very beginning did valium have a calming effect. This would have been the time before addiction began, approximately two months. After that they made me feel worse and by obliterating the ability to solve problems my sense of personal worth vanished.

Once thought processes are sedated by tranquilliser use you are not able to find within yourself any ability to cope with life. You do not know when you are doing something irrational. The doctors never emphasized that it was vital to stick to the stated dose, let alone use them only for the short-term. Taking more drove me out of my objective mind and I know when I resigned my job in the late 70's it was as a direct result of being on these tablets. I was paranoid and had many days off work. Taking more tablets is another consequence of the lack of self-control that the tablets create. Of course, I understand now that I could not have escaped the inevitable effect of tolerance withdrawal. I was merely hastening it.

Doctors believed they were prescribing for anxiety. When you returned to their consulting room they thought you were cured of it. They thought you were behaving as a rational human being as you looked normal and they could understand what you said. They did not appreciate that you had become passive. A tranquillised patient wants and can only accept short-term palliatives both for the physical discomfort of tolerance withdrawal and for the social and emotional problems that develop because of the suppression of self-control.

It is my opinion now that these medicines should not have been licensed for use by family doctors. There was no long-term study and the GP's received no training. They never looked for a pattern in symptoms presented, perhaps because they had been assured by the pharmaceutical companies that there were no real problems with benzodiazepines. They never asked critical questions such as what was this patient like before he began taking these tablets—is it possible the tablets are causing these further symptoms. They just treated each problem in isolation. I get very annoyed by doctors claiming they are scientists. Diagnosis in a surgery is only opinion. Their knowledge comes from their limited training, their limited experience, their drug reference guide and what the drug companies have told them in advertisements or at sales pitches.

My intake of valium gradually increased throughout the 70's. As the tablets were now suppressing any chance I might have had to achieve something in life, I found significance in listening to the doctors and accepting their treatments.

"You're depressed," said one of these general practitioners, as I asked for help with one of my physical symptoms, episodes of self-harm or emotional crises.

"Am I?" I said wonderingly, and Prothiaden, a tricyclic anti-depressant, was added to my list.

I am convinced the diazepam increased any depression I was feeling as a reaction to the problems occurring within my life of unrecognized addiction. With a clearer mind, I would have dealt with any problems that occurred naturally.

After some weeks off work I rescinded my resignation from teaching and worked my way back to a less stressful school, although I could not retrieve my previous job level as a team-leader. My wife managed to complete a teacher

training course. I was still using alcohol (the irony is that this is one of the freely chosen, freely available drugs that people use to help with stress). Extra tablets such as melleril and sleeping tablets were gradually added as I developed new symptoms or levels of anxiety that the doctors were sure they had the answer for. In one episode I unwittingly went cold turkey on valium—the incredible fear, inability to speak and racing heart I suffered may ironically have convinced the doctors I had a real psychological problem. The helpful GP brought a bottle of tablets to the house and the addiction was restarted. I also had hallucinations with Ativan when it was tried on me, but thankfully that warned me off this potent short-acting drug.

After six years coping in the more traditional school I made an unwise move and volunteered to be the teacher who had to transfer to a neighbouring school. This was not a course of action I would have taken had I been in control of my own mind. The stress of a new staff and an unexpected decision by that school to change to team teaching finished off my teaching career. Instead of arguing with the education authority that I had made it a precondition of my offer to move that I was not required to do team teaching, I took the easiest way out of the depressing and difficult situation and stayed off sick long enough to complete twelve years service. I knew I could then apply to retire on medical grounds and would receive a small half-pension. I finished in teaching around 1985 and I have not worked since. I saw two psychiatrists during the time I was applying to retire. They both reported back to the doctor that I was not mentally ill but was depressed.

We had three children by then, but as I needed care as well, my wife could not make the time commitment to enter full-time teaching. She could only do low-paid part-time work that did not keep her away from the house for too long. Following my retirement I had two courses of MAOI anti-depressants. Tricyclics, tranquillisers, sleeping pills and headache pills came and went. A psychologist was suggested but no appointment materialized, although there is no real way that an addict can respond to counseling. A community psychiatric nurse was mentioned at one time but I had no motivation to form a relationship with any new medical professional. Xanax seemed quite helpful—it would, I suppose, given its greater strength than valium, but it disappeared from the NHS List in the 1980s. At that time I must have gone through another experience of cold-turkey, as the drug was just stopped.

In the late 80s I was able to give up using alcohol. In the early 90s I was started on a new tricyclic —Anafranil. This drug did have a beneficial effect on my mental outlook for a while but no anti-depressant can deal with the negative effects of benzodiazepine addiction for long. The result was that I became “less prickly,” and easier to get on with in our very small family circle. This was very welcome to my wife and children. Two of its unwelcome side-effects were a considerable weight gain and high levels of acid for which I had to start taking antacid liquids and yet other pills. I began to suffer with neck pains for which I was eventually prescribed codeine tablets. I was sent to a rheumatologist to investigate the possibility of arthritis. He took 14 X rays but any conclusion seemed to be that there was no real arthritis problem.

In 1996, after many attempts over the years, I was able to concentrate enough to give up smoking. My level of diazepam had crept up to around 40mg per day, plus sleeping pills. The Anafranil had been changed to the generic chlomipramine.

WITHDRAWAL

In August 1999 my wife wanted cheaper car insurance and was asked to declare specifically for the first time whether either of the drivers took medication. The insurance company stressed that the DVLA must be informed. We did this and reported that I took daily between 30 - 40mg diazepam, about 6 x 50mg chlomipramine, and zopiclone and nitrazepam on different days for sleeping. (I did not drive much, having become a semi-recluse. In the 1980's I had, on my own initiative, asked my GP for a letter stating that my tablets did not interfere with my ability to drive. He willingly supplied a hand-written one.)

A letter duly arrived saying my case was being sent to the Secretary of State for Transport's Honorary Medical Advisory Panel on Alcohol, Drugs and Substance Misuse in Driving. In August 2000 this committee's verdict arrived. Although they appreciated I would have some tolerance to the drugs as I had been on them for many years, they felt these levels were too high for safety and they asked for the return of my Driving Licence. This totally unexpected blow struck right at my sense of personal freedom. I resolved to reduce my tablets in order to get my licence back.

I began to reduce my diazepam, initially at the rate of about 2 mg every fortnight, and went to my doctor to tell him my intention. I asked him which sleeping tablet the authorities would look most favourably on. He said he had no idea about the DVLA but he thought zopiclone would be better than nitrazepam. I also changed the anti-depressants to 12 x 25 mg to allow for more flexible reduction. The doctor gave me no information about anything—nothing about the necessity of doing it at a very gradual rate, nothing about the existence of withdrawal symptoms and nothing about the difficulties of those symptoms. I also started smoking again after a four year cessation, to distract myself from the intense

pains and sensations that began. I had put a great deal of effort into becoming a non-smoker and would never have taken up the habit again if the withdrawal symptoms hadn't been so severe. My wife was dismayed.

In November 2000 I wrote to reapply for my licence and received a medical information consent form. I saw my GP in December and asked him what level would be appropriate to get my licence back as this was my prime motivation. Again he said he had no idea about the DVLA. On this visit I asked for the number of my anti-depressants to be reduced to 6 – 8 x 25mg chlomipramine. My diazepam level was down to about 25mg. Again I received no help or advice at all. When I saw him again in January 2001 he had probably received DVLA papers as he said,

“I am duty bound to get you off these diazepam.” !

He never said why, and it seemed as if he thought it was his idea. As getting my licence back was my main motivation, and in the absence of any guidance on how to reduce, I pressed on with my reductions. I stopped both sleeping pills completely and asked for my prescription to be 4 – 6 x 25mg chlomipramine and about 20mg diazepam.

In February 2001 I developed agonizing earache. Another doctor in the practice could see no cause but he prescribed antibiotics. I developed tinnitus, became unable to go out of the house at all, and was thrown into a panic by unexpected noises such as the doorbell ringing. The antibiotics had no effect and I asked my wife to go and see my GP to explain my state. She asked for a home visit. When he came out he could see nothing wrong either but prescribed a second course of antibiotics. I told him that I could not sleep at all in this condition and even though I did not feel the zopiclone were effective, could I have them back on my repeat prescription list as I was desperate with sleeplessness. He told me I could take two if I wanted, but I pointed out that that way I would never get my licence back. I now know that tinnitus and earache are common withdrawal symptoms.

After several emotional and lengthy phone calls to the DVLA clerks in March and April 2001, informing them that their deafening silence was increasing my blood pressure and my anxiety levels, after I had put such a strenuous effort into reducing anti-anxiety tablets, I received a one year licence at the end of April 2001.

The tinnitus went on for several months. In June, with the licence settled, I managed to stop smoking. However I was also suffering even stronger limb and muscle aches by now and I gave in after a fortnight—I needed the cigarettes to take my mind off the pains and the insomnia. I would have periods when I could only achieve about 5 hours sleep in 3 days. I was taking more and more prescription co-codamol – 30mg codeine and 500mg paracetamol in a soluble form – to try and get some relief. We still thought it might be arthritis and my wife investigated helpful supplements. She acquired some vitamin C, a multi-vitamin and mineral, some glucosamine sulphate and various other health products for me to take. She also noticed I was getting very disturbed every fortnight as my ration of one hundred co-codamol was used up early. The prescription label said take up to eight a day so I knew of no harm in taking at least that, I was in such constant agony, though we did also make several attempts for me to do without them or limit my intake over this period.

While visiting my father-in-law in August 2001 I tried a toy mini-scooter. The next day I was knocked out by crippling pain and very uncomfortable perceptual disturbances. I had sensations of lights and movement coming at me while I was sitting as a car passenger. I was bewildered by all these symptoms. I reported my devastating body aches by letter to the doctor and sent a note with my repeat prescription request saying I had a constant ringing in my ears. He jotted a sentence on a post-it note with the prescription,

“Sounds like tinnitus, nothing to worry about.” !!!

This lack of help and understanding annoyed me greatly. I was suffering something unknown and the doctors were absolutely no help. During the autumn of 2001 I was exhibiting obsessional behaviour and irrational rages. I was very susceptible to sudden noises and shocks. My wife decided to start buying 8mg soluble codeine and paracetamol from the chemist to prevent me running out. I was still taking a lot to try and blank out the aches and pains and overcome the insomnia. Delays with my repeat prescriptions were major upheavals. I pressured my wife to go to the surgery on my behalf and try and obtain some effective doctoring to relieve my misery. In December she took an account I had written of my current, agonised state.

She was able to tell our doctor that I had not used my previous month's prescription for anti-depressants and he could take them off my list. At our request he changed the soluble codeine for 30mg dry codeine to cut out the massive amounts of paracetamol I was taking. He informed her that other patients managed easily on one hundred tablets a month. When this was relayed to me I had a clear enough mind by now to begin to understand that although the chemist's label said take up to eight a day, it did not actually mean you could take up to eight a day every day. There was no warning on the leaflet in the box that said that after a short while you develop tolerance and became addicted. Without asking, the doctor reduced the zopiclone to 3.75 mg. I had written that sometimes I took that amount. This annoyed me further.

However I was pleased with giving up anti-depressants and I decided that since I could feel no benefit from the diazepam, which was around 6mg a day then, I might as well do without them too. I found that I could not stay off them completely for long and went back to 2 – 4 mg. New symptoms that appeared were nightmares, grinding my teeth involuntarily, restless legs, jaw ache and a feeling of impending doom.

My second consent form arrived from the DVLA in December and I knew that when the doctor completed his part in January or February it would say no anti-depressants, 3.75mg zopiclone and about 4mg diazepam. I was hopeful of getting a full licence back. My wife and I both noticed that my critical thinking faculties were returning. For the first time in many years I was able to apply myself to everyday tasks and come up with creative solutions to small problems. I began to take an interest in the world outside.

By February 2002 I had begun to feel I was about to die at any moment. I could not get to sleep until sometimes four or five o'clock in the morning, often because my neck, shoulder blades, legs, arms and hands were so painful. Periodically I was awake all night. My feet were often swollen, my little finger burned, my mouth and lips were dry, swollen and sore. My face and scalp were numb. I had paranoia, high anxiety and almost complete agoraphobia.

In either March or April 2002 my wife pushed me back to see the doctor face to face. I was harbouring great resentment over his "duty-bound" statement, as it had been all my hard-fought effort to reduce the tablets, which had merely resulted in extreme discomfort and pain to me. He did not seem to take my symptoms seriously and I was incredulous that he could have been so ignorant of the DVLA's medical requirements. Of course I had to take more diazepam to actually get myself out to the surgery.

In this consultation I was amazed to find that both the doctor and his new computer had not registered the fact that I was no longer taking anti-depressants. (My wife composed a hurried letter to the DVLA to re-iterate this.) I explained my agonizing aches and pains to him again and he suggested that I had fibromyalgia. He organized six blood tests – for inflammation, thyroid, two vitamin deficiencies and other things. He suggested glucosamine sulphate was often helpful to people. I said I was already taking it. He said I needed to visit a dentist and this was probably what was causing my mouth soreness. All the test results were negative.

After another torturous wait with the DVLA, the clerks confirmed a doctor had decided on my case. A second one year licence arrived in the third week of June, to my great disappointment. I still felt the insurance company and the DVLA were the main villains in the suffering I had endured. My wife began to look things up sporadically on the internet on the rare occasions our son was not using his computer. She found some DVLA pages explaining official policy on the use of tranquillisers for licence holders. She also found some comments from Panorama's The Tranquilliser Trap which included some withdrawal symptoms which matched my suffering. I noticed in this period that I often had an uncomfortably hot body at the same time as painfully cold arms. I kept having hot baths and showers to soak them for some short-term relief. My mouth and lips were always sore and painfully dry. I was waking from sleep and realizing that I had stopped breathing and I was having extreme breathing discomfort during the day, particularly in warm weather. My body was often running with sweat and any stress or difficulty was wiping me out mentally. Total exhaustion set in—even if I had had some hours sleep, I could be exhausted within minutes.

She suggested that we both go back to the doctor and insist on some kind of diagnosis. We did not see how it was possible that all these varied and painful symptoms I was enduring could not have a cause that a medical professional should be able to recognize. I took some extra diazepam on one or two occasions around this time and discovered to my surprise that my saliva returned to normal. My mouth and lips felt bearable and the muscle pain lessened. I still frequently felt a terminal illness or my death was imminent. I now know all these symptoms I was suffering are frequently experienced by people withdrawing from tranquillisers, anti-depressants and painkillers, whether as part of a voluntary taper or because the level in their body has dropped below what has become necessary for maintenance of bodily ease (tolerance withdrawal).

We visited the doctor together at the end of July 2002. He again insisted my pain syndrome was called fibromyalgia and offered no suggestions for alleviating it or coping with it. We asked if it could be withdrawal symptoms and he either said no, or did not reply. He could still see no abnormalities in my mouth but agreed to get a specialist second opinion as my wife explained I was very worried I had oral cancer, being unable to do anything about the cigarettes I smoked. I explained to him that extra diazepam had brought my saliva back to a more comfortable level so that this particular one must be a withdrawal symptom. We were at our wits end and thought that taking more diazepam was the only option available.

"Do you want to be on these tablets for the rest of your life?" he intoned gravely.

I explained yet again how poor the quality of my life had become—the insomnia, the pain and unexplained sensations, the agoraphobia. What had I gained?

“I can raise the dose, but it is my duty to tell you that you must inform the DVLA” he pronounced.
(So he’d heard of it by then!!)

I walked out at this point—incensed by his high moral tone, his ignorance, his seeming lack of concern and the two years of stress, upheaval and suffering we had both undergone. My wife stayed a little longer to ensure she received the increased prescription for diazepam. He said to her that he was sorry he had upset me. He added that he could appreciate that the quality of my life was now very bad and increased diazepam might be the answer. (This man had treated me for thirty years since he was with the practice as a student.) My wife explained that I disliked the DVLA intensely as I thought it was the cause of all my troubles. In what she took to be a small apology for the suffering my withdrawal had caused (all started by his sense of duty, he thought!), he said with a little smile,

“I didn’t know he was a driver.” !!!

What on earth did he mean by that?? My wife repeated that they must be withdrawal symptoms as we had found similar cases on the internet. She also reminded him that he had written me a letter in the 1980’s affirming my fitness to drive while on all these tablets.

“Did I?” he replied.

In August I took some extra diazepam in order to make two visits to the dentist. Completion of treatment ruled out the doctor’s diagnosis of my sore mouth. The more recent symptoms of breathlessness, sleep apnea, chest pains and sweating developed alarmingly. At the end of the month my wife found Carole Packer’s website and benzo.org.uk. Everything became clear, including the episodes of cold turkey I had unwittingly endured over the years and the incredible cocktail of drugs I had been prescribed. We learned new phrases like “iatrogenic addiction” and “tolerance withdrawal”.

We were amazed at what we discovered—the complacency of Dr Jenner (the father of Valium) who said that “long-term trials were expensive and difficult to arrange.” There was also the apparent complicity and duplicity of the drug companies who realized GPs were a law unto themselves, that no one was looking over their shoulder making sure they learned and took account of new research. There were the short but clear 1988 and 1999 Guidelines created by the Department of Health that the doctors were free to ignore. There was the ignorance of the doctors and their inability to see any overall pattern in a patient’s symptoms. We read of the bravery of the survivors who had been through everything we had suffered, and worse; and the determination of the people setting up the campaign and support groups. We were also able to study the information available on fibromyalgia and addiction to codeine.

I told my doctor on several occasions over these years that I could not get out of the house. No comment, no help. He obviously did not see it as his problem. That was one of the things that angered me. He asked to see me on more than one occasion. I told him I could not get there, but there was no action on his part. It’s as though it did not register. He was willing to prescribe tablets to cope with the initial condition (as he saw it) but not to follow through and deal with the subsequent effects of his treatment.

I can believe that in the 1970s doctors were still ignorant of the independent research papers on withdrawal and addiction that had been published. Ramshackle paper records and the invention of repeat prescriptions meant that GPs did not have to constantly think about the patient’s problems, they only saw the patient when there was a crisis. They may not have known these tablets were terrifyingly addictive; that they removed your social inhibitions and the ability to think. They also turned people who were by nature introverts into extroverts for a time, which increased their anxiety levels as they found they had made work and social commitments that they were not at ease with. However from the 80s onwards, people were being let off jail sentences because of the effects of valium on their actions. There does not seem any excuse for remaining unaware from then onwards.

Time and time again over the years I have presented symptoms which were important pointers. I did not know then that they were important, but I do now. Obviously the Department of Health Guidelines have no legal status. Otherwise doctors could be sued because they did not follow them. The new leaflets in the packets now mention some side effects and caution you against stopping abruptly but they do not state that the biggest side effect of all is ADDICTION. People are usually paid compensation if they have lost thirty years through wrongful imprisonment. Even at a modest salary over the last 19 years I have lost at least a quarter of a million pounds and my wife has never been able to take a full-time job because of the care I needed. The state has had to pay out benefits to me over that time and we have both lost the chance to create a pension.

In the middle of September 2002, a letter arrived from “a prescribing support pharmacist” on behalf of our doctors. It advised us that “recently family doctors have become concerned about zopiclone, among other tranquillising medicines.” Apparently, it is no longer recommended for long periods of time, it may be addictive, and it should not be stopped suddenly as “you may experience unpleasant withdrawal effects.” !! Would I please consider cutting down or even stopping altogether (with the aid of a clinic they are organizing if necessary)!! They “believe this advice is a positive and forward step to a healthier future for you”. We had achieved the same result through our own hard-fought efforts with no help from the doctors. It is as if the Department of Health is hoping this step is sufficient and will absolve them from all blame in the shameful damage they have inflicted on so many trusting patients and their families. The reason behind the appointment of someone to oversee doctor’s prescribing habits is of course to save money on prescriptions or to evade responsibility for the mass addiction situation the NHS has created. The government is prepared to avoid responsible action in the interests of the NHS, the economy, the drug companies and politics, but not in the interests of the patients who have been guinea-pigs for mind-altering drugs that have generated enormous profits for private companies. Are tranquillisers and anti-depressants the modern bread and circuses?

I have been able to give up all medications but at a great cost to my health. I have not felt physically well for nearly 4 years now, but interestingly all the psychological handicaps I once had have all disappeared along with the drugs. I feel more in control of my life. I can utilize my Mensa level IQ, I read several books a week on a wide range of subjects, forming opinions and communicating my views. I am planning and tackling all sorts of projects that have been neglected for twenty years—household, electrical, DIY and gardening. Unfortunately, for thirty years we have lived in the middle of a badly-maintained, low-income, socially stressed council estate. My recovery may be too late for my wife to utilize her earning potential to enable us to move to a pleasanter environment, the sort of place that one would normally expect two qualified teachers to be living in.

SOME OF THE SYMPTOMS I HAVE SUFFERED DURING 30 YEARS OF ADDICTION, TOLERANCE WITHDRAWAL, UNINTENTIONAL WITHDRAWAL AND INTENTIONAL WITHDRAWAL

Physical

Impotence
 Heartburn with Anafranil
 Constipation
 Pains in the wrists – diagnosed by the GP as Carpal Tunnel Syndrome
 Chronic pain in the neck
 Frequent headaches – GP diagnosed them as stress headaches
 Very fast heartbeat – one GP listened to it and said “You’ve got a very good heart.”
 Eczema – hydrocortisone prescribed
 Rosacea – aspirin and salicylic acid cream prescribed
 Raised blood pressure – a tablet prescribed
 Splits at corners of mouth
 Globus
 Increase in weight
 Swollen feet and toes
 Sore and enlarged testicles
 Lack of activity
 Painful jaw
 Grinding teeth
 Aching limbs
 Hot body, cold arms
 Sore, swollen and dry mouth and lips and tongue
 Face and scalp numb
 Chest pains
 Breathlessness and feeling of breathing through a mask
 Aching shoulders
 Insomnia – could not get to sleep because of pain, woke several times a night, woke too early.
 Tinnitus
 Earache
 Nausea and vomiting
 Oral thrush
 Constipation
 Irritable bowel syndrome
 Raised cholesterol levels

Mental

Inflicted wounds on myself with knives and airguns
Panic attacks
Kleptomania
Fear of being alone
Thoughts and feelings that I was about to die
Inability to read
Loss of memory
Depression
Anxiety
Hyperactivity
Fear of insanity
Demented and murderous thoughts
Suicidal feelings and two attempts
Hysterical and inappropriate laughter
Nightmares
Obsessional behaviour
Feelings of worthlessness
Derealization
Depersonalization
Hallucinations
Paranoia
Quick mood swings
Irrational rages – threw things out of windows and broke things. Jumped out of upstairs window
Phobias

Over my 30 years as an iatrogenic addict I was prescribed at least 42 different pills, potions and creams. Some were prescribed for years, some for shorter periods of time. None of them were needed after withdrawal but they left their mark.

With the knowledge I have learned recently about the effects of diazepam and antidepressants I know that this bizarre and painful collection of symptoms that I suffered throughout the last thirty years was caused by the drugs themselves and was treated by the drugs themselves.

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September 2002