

Camouflage for Medical Practice or Real Assistance?

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Stopping Long-Term Benzodiazepines and Z Drugs - A sample letter

This is a sample letter from the web that has been widely used to write to patients who are on long-term tranquillisers and sleeping pills. A variation of this letter sent to me can be found below.

Dear

I am writing to you because I note from our records that you have been taking a medicine called for some time now.

Recently, family doctors have become concerned about this kind of medication when it is taken over long periods. Our concern is that the body can get used to these tablets so that they no longer work properly. If the tablets are stopped suddenly, a few people experience withdrawal effects. Research shows that repeated use of the tablets over a long time may actually cause anxiety and sleeplessness and that the tablets can be addictive.

I am writing to ask you to consider cutting down on your dose of these tablets and perhaps stopping them at some time in the future. The best way to do this is to cut down very gradually on your tablets (for example, if you take three tablets, reduce to two and a half tablets; or if you take one tablet divide it in half). You should make these changes slowly over a period of two to four weeks. In this way, you might be able to make a prescription last longer.

Once you have cut down, you might be able to think about stopping them altogether. Most people even feel better when they are off their tablets.

If you would like to talk to me personally about this, I would be glad to see you in the surgery.

Yours sincerely

My main objection to these letters is that what they say was not particularly true - there was no recent concern because of recent research on the part of family doctors - it was a camouflage for licensed drugs which turned out to be dangerous and negative for many. It was a way to not involve doctors (who still continued to over-prescribe) in their own responsibilities. When I received one I had almost completed withdrawal myself and had taken the first steps towards understanding what was going and had been going on.

There is a blank space in the suggested letter for the insertion of a drug name - a Z drug (zaleplon, zopiclone or zimovane) or less usually of a benzodiazepine such as Valium (Diazepam). In my case I never received one about benzodiazepines which I had been taking for nearly thirty years so presumably there was no concern on the part of family doctors about them in the area where I lived!

There is no real advice in these letters about how to stop and the letters are therefore dangerous, though in the eyes of local NHS administration they can be pointed to as an attempt to get people off - positive action. The letter (including the one sent to me and reproduced

below) shows no understanding of the seriousness of withdrawal - maintaining ignorance really should be the motto of the Department of Health.

Mary Baker who has attempted to help many people over the years produces some salient points below and they are well worth reading. Those who have personal experience of benzos will understand what she is saying though others may not.

These sample letters. I agree, it is the back-door approach of reducing benzo prescriptions only and abdicating their responsibility for patient care with incorrect information. For instance, when does the patient reduce their dose - every day, or once per week? Or do they reduce it every other day or once per month?

Most patients would be very frightened and not want to see their doctor but would have no clear idea of how to reduce or when, or what to expect in the way of withdrawal symptoms. Some being too drugged to know they would have withdrawal symptoms.(my experience)

I believe that many patients would try to reduce on their own for fear of being taken off the drugs, make a hash of it, become very ill, reinstate the drug, to feel better, but would remain ill. Then it's too late, the damage has been done. And ill patients are far too ill to start reducing all over again. That is why patients should be prepared well in advance on how to manage their drug withdrawal with all relevant information to hand and constant support.

And to state 'most people even feel better when they are off their tablets' we know is totally incorrect. Most patients cannot even imagine in their wildest dreams what it is like to live without benzos because it doesn't bear thinking about. Plus, for many patients it is long forgotten what life was like prior to taking drugs!

They also stating 'if the tablets are stopped suddenly, a few people experience withdrawal effects'. Some patients may even think, in ignorance, okay, I can handle that because I'm fed up with taking these drugs for years anyway, and stop taking them. (my experience) We know the outcome of stopping benzos suddenly, cold turkey and the possibility of fits and death. And are these letters targeted and discriminatory? Are they being sent to elderly patients or anyone living on their own?

People need to know about this treatment, by letter. Not forgetting that most GP's have not had proper training in benzo drug addiction, benzo illness, benzo drug tolerance, benzo adverse effects, side effects or benzo withdrawal symptoms, and post withdrawal symptoms, plus the permanent damage coursed by taking prescribed medication for far to long.

Tell me, is this how doctors are treating their patients who have dementia? Do they just send them a letter and say, just pop in to talk about treatment for your dementia? Would these doctors really think that anyone with dementia would actually remember what was said during the appointment? No. They would not. Yet these benzo patients are known to be suffering from a drug induced dementia. They are seen to be forgetting all the time - see Prof. Lader's research, which is very telling on how these benzo patient are thought to have dementia by doctors, especially the elderly, whereas, their short-term memory impairment and confusion is due to taking benzos.

And so these patients, in particular, need to have 'written' information, preferably Prof. Ashton's manual, given to them 'prior' to reducing from their drugs, so that they can read and re-read it again, how to safely withdraw. And even then, many/most patients will not remember what they have read! That is why patients who do have the manual, call it their bible, for they have to refer to it on a regular basis. Every doctor should be giving this manual out to all their addicted patients as part of and for their information on treatment for coming off benzos. It should be

supplied free on prescription-free information to all benzo patients, just as other patients are also entitled to have and are supplied with- free information on their health conditions.

These disgraceful cop-out letters that replace proper treatment and consultation with patients, make me so very angry!

Mary Baker

P.S. Not forgetting that these patients have drugged induced short-term memory problems, so even if they do consult with their doctors, they will forget most of what has been discussed! (my experience also)

Important Advice

Dear Colin Downes-Grainger,

I am writing to you because I note from our records that you have been taking Zopiclone for some time now. Recently, family doctors have become concerned about this kind of tranquilizing (sic) medication when it is taken over long periods. The concern is that the body can get used to these tablets so that they no longer work properly. If you stop taking the tablets **suddenly**, you may experience unpleasant withdrawal effects. Research work done in this field shows that **repeated use of the tablets over a long period of time is no longer recommended**. More importantly, these tablets may actually cause anxiety and sleeplessness and they can become addictive.

I am writing to ask you to consider cutting down on your dose of these tablets and perhaps stopping them at some time in the future!

The best way to do this is to take the tablets only when you feel they are absolutely necessary. Try to take them only when you know you have something to do which might be difficult for you. In this way you will be able to make your prescription last longer and longer.

Once you have begun to cut down, you might be able to think about stopping them altogether! It is best to cut down gradually and then you will be less likely to have withdrawal symptoms.

In the future we will be running clinics to help patients manage their reduction of the drug. If you would like to know more about these clinics please contact the Practice Manager.

We believe this advice is a positive and forward step to a healthier future for you, so please give it your most careful consideration.

Yours sincerely

E. Walker

Prescribing support pharmacist on behalf of Dr John, O'Flanagan, Smith and Ingledew

My Reply

7 November 2002

Dear Elizabeth Walker,

I am writing with reference to the letter and 'advice' you sent me on Dr John's headed notepaper at the end of September concerning my prescription for Zopiclone.

So sleep problems 'are not as damaging as you might think'

Well there are no problems as regards the NHS drugs bill, it goes down.

There is no problem for doctors, out of sight is out of mind, and past damage is water under the bridge.

There is a problem for patients innocently caught up in hypnotic addiction and withdrawal:

- Disturbed sleep patterns/no sleep, which often made it impossible to go out to work.
- Disturbed sleep patterns/no sleep, which may well have made it dangerous to work with machinery.
- Disturbed sleep patterns/no sleep, which places the individual who drives in a potentially criminal position in the event of an accident.
- Disturbed sleep caused by benzodiazepines and ineffectually managed by Z drugs.

There is no treatment or antidote for the physical withdrawal pains, going on for months and even years in some cases, which follow long-term addiction to sleeping pills - benzodiazepines or otherwise.

It has long been common knowledge among experts with open minds and those who wish to become aware, that hypnotics are not effective after a surprisingly short time, and that use after that is merely feeding a dependence and staving off withdrawal symptoms. But you do not address this issue.

Informing people about Zopiclone, whatever the motive, is of course an excellent policy, but you should be informing doctors, not addicts retrospectively. Normal everyday insomnia may not be a great problem, the real problem is the uninformed over-prescribing by GPs. Addressing your centrally provided letter to addicted patients who may have been taking sleeping pills for years or decades, is not only inappropriate but downright misleading and dangerous, not least because it is being sent out in isolation, -divorced from patient circumstances.

Family doctors have NOT recently become concerned by RECENT evidence - the evidence goes way back and many of them ignored it. Frankly, I doubt if they are much involved in this medical message', particularly since local pharmacists say that new prescriptions have not reduced particularly.

You ought really to consider whether it is advisable to omit details of withdrawal symptoms. If Pharmacy Advisers are going to be the main source of advice on benzodiazepines and similar drugs such as Zopiclone, then you might consider it a positive step for patients to make an attempt at filling in the blanks that family doctors have left open for forty years.

The most effective and efficient way of saving the NHS money on its drugs bill, is to advise doctors to read back numbers of the British Medical Journal (Br Med J, 1980:280,910-912 is a good place to start) and also to read the various PILS leaflets, the relevant BNP advice and the CSM Guidelines, basic though they are.

I had already started to withdraw from Zopiclone some time before your letter came, and I had been withdrawing from Diazepam for more than 18 months (after I discovered by chance the harm it and subsequent drugs were causing). I have to tell you that I have not experienced 'limited side-effects' in spite of a much more gradual and scientific reduction than you

recommended. In the first six months after beginning a withdrawal and achieving a cessation of use, I lost the equivalent of three months' sleep.

Some nine months after the last portion of tablet, going to steep at night is still very problematical, and exhaustion is a daily feature. This experience and worse is widely reported, but of course is totally unaddressed where it matters.

One final point - recommend to those with the power to make decisions, that the Area Health Authority buys copies of the Ashton Manual (Professor Heather Ashton, DM, FRCP, Newcastle University) in bulk, and sends them to all doctors in its area - it really is very informative. You will be able to read it online at the website www.benzo.org.uk/manual should you wish to check it out first.

Yours sincerely,

Colin Downes-Grainger, 11 September 2009