

**Examples of Emails received by Millie Kieve of APRIL  
(Adverse Psychiatric Reactions Information Link)  
August 4, 2011**

1. I had horrendous adverse reactions to benzodiazepines to the point I could no longer function on the drugs, then was subjected to 4 years of terrifying withdrawal and associated syndromes in trying to discontinue. Truly a clever trap. I knew nothing of the pain and suffering I would have to endure when I started taking the damn drugs. Counselling would have worked for my anxiety, or I could have just stopped the Prozac that caused the anxiety in the first place. I was given the Prozac for a head injury associated with a fainting spell. The doctors decided I was 'depressed' when I told them I felt I needed a month on the sofa to recover from the head injury.

2. Please can you tell me how to withdraw from temazepam with the least side effects.? I have been on them for about 2 months and already have bad withdrawal symptoms when I try to cut down, such as panic attacks, terrible palpitations, general ill feeling and breathlessness on exertion. The dose is 10 mg and I have cut them back to 9 and a half mg. I think the problem maybe that until 2 weeks ago I was taking 1 zopiclone (7.5 mg ) for about 4 nights and then 1 10 mg temazepam for the next 4 nights and since 2 weeks ago I have kept to the 10 mg temazepam so in effect I have cut back too drastically because 1 zopiclone equals 2 temazepams so I understand. Do you agree with this?

I would be grateful for some advice as my doctor is not very helpful.

3. After being on anti depressants (8 different ones which didn't work) and having hypothyroidism I was given diazepam. When I realised they were making me worse I sought help to com off them. I was to reduce them slowly over months and when I got down to 1mg I ended up in hospital after phoning 999 as I thought I was dying. I really lost the place - hallucinations and unreality. They put me back on 4 mgs which my addiction nurse took me off in 10 days. I am really suffering and can't get my thought processing to work and I am living in the past most of the time. I also have severe anxiety which leaves me housebound a lot - my husband does the shopping as I can only go to the local shops now and again. I am wondering if I came off the last dose too quickly. I just want to get back to myself again and to be able to live a normal life. Is this usual in withdrawal?

4. I am contacting you on behalf of my father, who has just been released from our 3rd stay in a psychiatric unit due to benzo withdrawal. Please contact me if you have more information for me. I was astonished to read on your website what these drugs can do to a person. He took some form of benzo for 20 years!!! My sister was ill when she was a child, and the doctor gave my parents something to "help". He's been hooked ever since. The symptoms started slowly, when he began feeling suicidal. I took him to the ER at a local hospital, and they admitted him to the psych ward, also the detox floor, because he was also an alcohol drinker. They thought he would have withdrawal symptoms from the alcohol.

You would not believe what we have gone through.

5. Zopiclone/ Zimovane a non benzodiazepine hypnotic with the same dependency problems as the benzodiazepines.

An elderly man had been prescribed, a drug with known dependency problems. The doctor having proclaimed that the man was depressed in spite of the patients denial that he was. He had recently retired and had a prostrate problem. At 6.30 am I decided to 'end it all' by taking 6 pain killers and 6 anti-depressants. Took a very sharp knife with me to a field nearby. Took the pills to no effect and decided to stab myself through the chest to my heart. Penetrated the skin on my chest but couldn't push the knife any further. I have never contemplated suicide before. The Zopiclone was to blame since I was trying to 'come off it'. I had been taking two tablets per night and had reduced it to half on the night of 19/20 August. Didn't sleep from 12:30 am and got up at 6am and tried to commit suicide.

6. To whoever it may concern

I have a question that has been driving me crazy that no one seems to have any kind of answer for or know enough about, except my doctor, but he is hard to reach.

Last year, I had brain surgery at the London Health Sciences Centre Epilepsy Unit. It has been close to a year seizure free. Therefore, my neurologist has been taking me off my medication for the past 8 weeks. I was on 4 clobazam pills a day. 2 in the morning and 2 at night, now I am on a half a pill in the morning. I do not know what is going on with my brain, but I can barely think properly and feel like one day I was a great university student, with a GPA of 3.47 last semester and now I feel like I am on a grade 4 level. My mind is not the same and I am assuming that I am having withdrawal symptoms. But it is hard to know that, at one point, I had all these mental abilities and was able to perform well enough. And now, I know that if I am the way I am now, I will not even have the capacity to return to university and ever reach the GPA of 3.47 again.

My question is, will I gain remission of my mental abilities once off my medication and is this normal? I am at the point that, if I knew I had to live like this for the rest of my life, I would go back onto my medication in a flash. Please help me, I have no clue what to expect next and am kinda scared, actually really scared. I know nothing, and do not have much encouragement, except for people who have no clue what My mind is going through to support me. I can barely sleep, because my brain is so active, it barely gives me sleep and I feel like it is taking over.

I replied and received this response:

Thank you for your response. I didn't know if I should have written you back, because in the mist of the emails, I read something about paying money for medical advice, and that scared me because I don't have any money. But I thank you greatly for repaying. I seem to be having a lot of the withdrawal symptoms. But now I know what can be expected and am very grateful. I had a craniotomy, (something like that) where they removed some of my right frontal lobe area. They operated on my right side. I had scar tissue on the right side of my brain, which is now gone, they took it out. Thank you so much for your time, you have helped both me and my mother understand more. Coming off this drug is like going through hell and back. I would not wish it on my worst enemies and I just hope and pray that it will be over soon. I have been on anti-epileptic drugs since I was 2. For about 18 years of my life I have been on drugs to control the epilepsy. More importantly, from this email, you have giving me and my mother much hope in regards to a recovery and gaining my abilities back. I was so scared that I was going to be like this for a long time. Several months is a long time but less then a lifetime.

Thank you very much, you are much appreciated!

7. Can you give me some advice please. I have just visited your web-site via a link and whilst reading some of the cases it made me think of my mother and wondered if she actually fits the criteria. Two months ago she was diagnosed with pneumonia, she was near to death but did pull through. She has been taking Loprazolam for at least 40 years and when she was ill because she was sleeping all the time, the doctors took her off the Loprazolam. When she started getting well, she was practically un- recognisable. A calm placid lady of 81 became a foul-mouthed fishwife, this woman who had barely sworn even to chastise errant children had now become horrid. She was rude to family, terrible to the hospital staff that were trying to nurse her and even violent, she attacked a patient and a visitor until in the end she had to be given Risperidone. She is home now and appears calmer. Can you tell me what questions I should be asking the psychiatrist and what help there is for me - the carer.

I responded and received the following:

Thank-you for your prompt reply, I sometimes feel that I am banging my head against a brick wall. It is reassuring to be able to "offload" to someone who knows what you are going through. I would like you to pass my details on to the lady who's mother was on Librium. As yet I am still unsure about the A.D.R. I feel I do not know enough about it to start pointing a finger. Although I am open to any information you think could help me. Thanks again.

8. I'm 8 months off benzo. the first 5 months were much better than now and I'm afraid I have permanent damage. At first my main problems were insomnia and a mild fatigue. 3 months ago my fatigue got really bad to see me housebound and I started suffering from severe multiple chemical sensitivity, any smell now is really bad, even my baby shampoo. I'm desperate I cant live this way all my life. Why am I feeling worse? how do I know if I have a permanent damage? I have a horrible metallic taste and nausea that develops after I have a chemical allergy. I was diagnosed

fibromyalgia and another one CFS. Somebody told me to try a naturopath. I have many other symptoms, but these are the most scary ones. I know some people never fully recovered. I'm 44 and was on benzo for almost 25 years. please, help!

9. To whom it may concern. I am requesting some information and support regarding coming of clonazepam cold turkey after 2 years. Are you able to offer some support in any way for me. I have been of this drug now for 6 months and have experienced some awful withdrawal symptoms. I was told by my Doctor this was not an addictive drug and for quite some time while taking this medication I was on up to 6 a night. I at no stage tapered down and when I went cold turkey I thought I was going to die. What I would like to know are you able to offer any support for what I experience now is it because of the drug and symptoms I experience all related to coming of this medication. I would appreciate any assistance related to my problem. Many thanks.

10. At present I am on a withdrawal program from benzodiazepines after having used a dose equal 55 mg diazepam pr. day in 19 years, GAD and Social Anxiety. I'm now at 20 mg, and I feel like I have less anxiety!! Is this possible during a fairly, not abrupt, but not an overly slow withdrawal, to feel less anxious? It should have been the other way round, and when I was withdrawing from self medication on alcohol about 25 years ago I nearly reached the level of delirium.

Is it most likely a sort of fooling myself thing, result of wishful thinking, a placebo thing in a sense, that one day soon to come I may wake up and feel quite different, that the symptoms are yet to come, or is it possible that I can come through this fairly easy?

I had no idea of how dangerous these medicines could be. The last years have I not even been able to listen to music or go to the shop, but I was not aware that it was due to the medicines, I thought it would have been even worse without them.

I was first given Valium as a young teenager. I took it without regularity for many years. As of the last 6 years, I took about 12.5 to 15 mgs. each day upon advice from a doctor. After a total of over 30 years "familiarity" with the drug, the very same doctor cold turkeyed me from the Valium during January and February of this year. Needless to say, I have not been able to work or truly function since then. I was fortunate to have contacted Dr. Heather Ashton who told me that I would not stabilize on the drug again but would have to do a taper from the 15 mgs./day dosage I was placed on during March after I almost didn't survive. It is now almost the end of October and I have tapered to 1.5 mgs. with great difficulty. I have really seen very little "peace of mind" and have had to reassure myself regularly that everything will eventually be all right. I was once a very intense but paced education specialist for the state government and I am hoping to return to that job.

That is actually my question to you! I know that I have several weeks to go to taper down and off; then I have a period of letting the diazepam leave my system - almost 2 months! After that I worry about what will happen to me. Will I remain in withdrawal? Will I ever get well? Will I be myself again? I continue to experience low-level delirium and confusion, pain and depersonalization from the taper and I am guessing the cold turkey. Has that damaged me?

I thank you all for being there for all of us who have suffered or are suffering as a result of this terrible drug and uninformed doctors.

11. I've just read the warning signs of drug intolerance on your website. My mum has been taking Clonazepam, 3-4 tablets of 0.5mg per day, for 18 years for seizures, after about 2 years she found out they were in the same family as Valium and tried to stop taking them. Unfortunately against advice she completely stopped them over the space of 1 week. She had a psychotic episode & although she started taking them again, has been mentally ill ever since. She's been diagnosed as suffering from Psychosis, and then Paranoid Schizophrenia, but none of the drugs seem to work (although she doesn't seem to stay on one particular drug for long enough). The consistent throughout is she takes Clonazepam every day. I have written to Professor Ashton who has written back saying that it may be possible the drug has caused my mother's mental illness symptoms but couldn't confirm anything from distance.

Because of her paranoia we would find it extremely difficult to persuade her to withdraw following the correct guidelines, and her GP continues to prescribe them and doesn't seem interested. She doesn't have a permanent psychiatrist (hers has left), so I wondered if there is a medical

professional my mother could see who would be able to make an assessment of my mother & decide whether or not her symptoms are drug related or is suffering from a mental illness?

I'd really appreciate any contacts or help you can give.

12. We deeply regret that we will not be able to attend Conference. I have been putting off a discussion hoping that I will recover from this awful flu-like illness that has troubled me this past two weeks and just turn up.

I made the mistake of getting out and about last week hoping to "shake it off" but it did not work. Seem to be troubled badly with this sort of thing and conclude that my years of addiction to drugs has perhaps caused some damage to my immune system. I know things will go deservedly well for you.

13. I believe my mother is suffering from Protracted Benzodiazepine Withdrawal Syndrome. She withdrew abruptly after about 10 years of clonazepam at 5mg a day.

Mum took an paracetamol overdose. No one, including herself, put this down to the withdrawal from clonazepam. My dad had left my mum 5 months previously, and everyone thought she was in such a bad state because she couldn't cope with the marriage break-up.

Mum took a second paracetamol overdose and this lead me to seek psychiatric help. Over the last year Mum has taken venlafaxine, risperidone and lithum all to high doses - and hasn't really responded. Two weeks ago, she took another overdose (again paracetamol).

I have now started to find evidence that suggests if Mum was to go back on a benzodiazepine, her condition may greatly improve. However, the psychiatrists I have spoken with don't seem to agree - or even want to acknowledge that Mum's severe depression is due to the abrupt withdrawal from clonazepam.

APRIL, if you can offer and advice or help about what to do, or who to contact, in order to help my mother, I would be wholeheartedly grateful.

14. I was prescribed Clonazepam (1 mg a day) and Zyprexa (5 mg a day) for 3 months and 6 months respectively to treat a supposed brief psychotic episode. During treatment I continued to complain of mental slowness, bad memory, depression, anxiety, and poor concentration. I also suffered many other symptoms that I dismissed in an effort to deny their existence and hope that nothing is wrong, such as reduced verbal eloquence, confusion and unclear thinking. My doctors refused to acknowledge that this may be due to drugs. I eventually went off the drugs myself (the Clonazepam, 3 months ago, and Zyprexa 1 month ago) without consultation and now the symptoms persist. This is extremely frightening. I have just begun to research the effects of benzodiazepine withdrawal and am terrified that I may have damaged my brain forever. I used to be an honours student in.....and I desperately want to return to school. If you could give me any advice on how to manage my impaired cognitive ability and what sufferers do to get better, or a support contact that I can contact, I would very much appreciate it. Please help. I feel alone and hopeless.

15. I tried to go cold turkey. I was sick for 5 months and finally went back on it. My psychiatric symptoms disappeared in 20 minutes. How do I get of this drug without losing my mind?

16. This lady sent me a link to her story an appeal for help published in Wales - please read this:

[http://www.walesonline.co.uk/news/wales-news/tm\\_method=full&objectid=16696317&siteid=50082-name\\_page.html](http://www.walesonline.co.uk/news/wales-news/tm_method=full&objectid=16696317&siteid=50082-name_page.html)

17. I took massive quantities of benzos for more or less 25 years. I have taken none for the past year and still long for stress relief for every single second, of every single day. The medical profession made me an addict, it also convinced me that the mess my life became whilst benzos ruled it, was completely, and utterly, my fault. Now that I have stopped taking the pills, doctor's simply want to ignore me. I don't sleep, I don't answer the phone or the door. I keep my curtains closed and I tremble all the time. Yet despite getting myself clean, they want nothing to do with me. I recently had an interview to maintain my claim for incapacity benefit and left with the distinct impression that because I am off 'medication', I am no longer ill enough to require support. If they force the work issue on me I think it will negate any tentative progress I have made. I am so angry

I cannot find adequate words-how can a system that created so many chronic addicts, remain so disgustingly complacent and indifferent? I am on the verge of total dismay...I have to ask myself if there was any point at all, to my going through the abject torture of withdrawal. Sorry to rant, but I have rarely been so angry or frustrated. Thank you for being there, groups like you are a very bright light at the end of a very long tunnel!!

18. I have been taking benzodiazepines for about 8 years. At first I had no idea what I was dealing with until years later being prescribed every month for the last 2-3 years...I have had the most horrible anxiety within a day or two after being without. The feeling is astronomical; I feel like I am in a movie watching myself; or in a horror film with some one chasing me, etc.. I now am taking Ativan (2mg) just once a day. That is way down from before. Is there any hope at all? I hate being a slave to this "medication".

I responded and received this comment:

I REALLY appreciate your compassion and advice, you have given me hope that life is possible after this. I will for now stay on the "regular" dose...I think that maybe a 30 day pill reminder would be good, therefore I could take less over a couple of months, at the most, if that what it takes. I have the tendency to "make up" when I do it too fast. It's good too know there are other people out there that have gone through this. Again, thank you very much for responding and given advice; it seems to be hard to find people here that can admit to their problem, etc. Take care.

The following is edited but describes the problem of no specialist help being available for the majority of people in the UK.

19. History of treatment for minor anxiety. I live with my wife and own a business.

My wife started suffering from anxiety relating to my her employment. She became anxious and depressed and subsequently spent three months at home sick. I became riddled with guilt because I felt that she should not have to clean houses for others at the age of sixty two and started to slide into anxiety. I went to my GP in and explained the situation. I was not sleeping well and was concerned for my wife's welfare.

My GP prescribed

- 1, an anti depressant,
- 2, Diazepam to flatten any anxiety
- 3, Temazepam to help with sleep

I was advised to take up to 6 mg of Diazepam up to four times a day if I felt it was necessary and one 20 mg tablet of Temazepam at night. Initially the treatment seemed to work. I started sleeping better immediately and the anxiety attacks were suppressed by the Diazepam. The treatment carried on for a couple of months. At the end of this period I felt that the anxiety had not abated but was getting worse and the sleeping tablets were losing their sedative effect. My GP increased the dose of Temazepam from the original 20mg to 30mg and prescribed more Diazepam. The anti-depressants didn't seem to be having any good effect so he changed their type.

The year wore on and by September my anxiety started to go through the roof. I was by that time taking 40mg of Temazepam each night. Between September and Christmas big changes started to occur in my persona. All my emotions slid away from me and slowly my will, ambition and any feelings I had for living disappeared altogether as did my appetite. I lost 1½ stone in weight. I gave up alcohol as it gave me no pleasure. I also became totally acrophobic. I continued to work up to the Christmas break but by then the black hole of fear and anxiety reached catastrophic proportions. In September my GP had asked me to attend a course of treatment with a psychologist which I did.

In January, immediately after returning to work I collapsed into bed and spent almost a week asleep. I thought that I had a bug at first but I believe my body and mind had, simply shut down. I tried to get better by taking vitamin supplements. My appetite had disappeared but I was trying hard to force food inside me. I remember feeling cold, so very mind numbingly and painfully cold all winter through. As a consequence of this condition I have only worked an average of 2 days a week.

In February I started to feel that this terribly situation was not being helped but exacerbated by the drugs which I was taking. I don't know why but I started to become frightened by thoughts of drug

addiction. I did not know why I was reacting so badly to situations in my life that I had always loved, like being around happy people, going to work and having a good social life. I talked to my GP mid February and told him that I wanted to try to give up the drugs and he agreed that I should if I could. I started to cut down the drugs slowly and stopped taking them.. My GP said that I had been very courageous stopping the drugs. After phasing out the drugs I started suffering with severe withdrawal symptoms.

I am still sterile emotionally. I feel nothing and there is no feeling of well being in my life. I live in a very small dark world with fear and dysfunction as my only companions. I can not work or function properly. I can not even concentrate on calculating simple measurements.

I had no idea until started researching the benzodiazepine issues in April 2006 that the drugs were as harmful as generally described.

My GP said in February that he had referred me to the Area Mental Health Team. I have spoken to a P.A.L.S. officer recently who has checked with the Area Mental Health Team and no such referral has been found to exist.

My GP:

- 1, Did not warn me that the drugs could be addictive
- 2, Did not produce a treatment plan
- 3, When I told him that I wanted to reduce the dose with a view to coming off the drugs he did not offer a tapering plan

My GP has stated on three separate occasions that: -

- 1, He can not help me any further with this condition.
- 2, He can not refer me to anyone who can help me further.
- 3, He knows of no tests which exist to determine if I have sustained any short or long term neurological damage as a result of the treatment.

Drugs prescribed

5 different anti-depressants in 10 months.

Diazepam up to 30mg per day to be taken as required for 11 months.

Temazepam up to 40mg per night for 11 months.

Current symptoms are as follows.

Psychological symptoms

Agoraphobia

Restlessness and inability to concentrate

Short term memory loss

Lethargy

Total emotional blunting

Lack of will and ambition

Withdrawn sense of well-being inducing a feeling of loss and blackness without hope of any future contentment

Physical symptoms

Weakness and general physical debility

Excessive need to urinate

Headaches and bursting sensations surrounding the brain

Altered sensations and tingling in the muscles and skin, Patches of numbness

Sore eyes and burning sensations in the facial skin

Tremors, jerks & spasms

Trembling & shaking attacks

Feelings of electric shocks  
Swollen and painful joints and muscles  
Severe sweating painful cramps (at night)

Current situation

Two weeks ago I changed my doctor. He is a breath of fresh air in that he admitted that he has no in depth knowledge of benzodiazepine withdrawal but that he will research the situation and together we will try to find a specialist in this field who can, firstly, accurately diagnose the problems of protracted withdrawal and determine the extent to which I may have suffered damage as a result of taking the drugs for a period of 11 months. Secondly to consider the longer term support that may be available to me within the health service.

Please can you suggest a specialist consultant or a psychiatrist who my doctor can refer me to who could fill the above criteria.

=====

Millie Kieve

Chair/founder APRIL [www.april.org.uk](http://www.april.org.uk)  
Chair Yellow Card Advisory Group to Patient Reporting Evaluation Project -  
Link to report: <http://www.hta.ac.uk/project/1628.asp>

Address: APRIL  
Room 311 Linen Hall  
162-168 Regent St  
London W1B 5TD  
Telephone: +44 (0)20 7998 1561  
email: [millie@april.org.uk](mailto:millie@april.org.uk)

=====

APRIL  
Adverse Psychiatric Reactions Information Link  
Charity registered in England No.1072305  
Web site: [www.april.org.uk](http://www.april.org.uk)  
APRIL blog: <http://aprilcharity.blogspot.com>

View our 2008 conference and personal stories:  
<http://vimeo.com/user1816628>

Please be sure to obtain medical support to reduce or stop medication IT MAY BE DANGEROUS TO STOP TAKING SOME MEDICATION SUDDENLY.

PLEASE REPORT SUSPECTED ADVERSE DRUG REACTIONS (ADRs) in UK to:  
<http://www.yellowcard.gov.uk> <<http://www.yellowcard.gov.uk/>> to report on line.

You may also give details over phone, or request a Patient Yellow Card form to be mailed to you, between 10am - 2pm only 0808 100 3352

Report ADRs USA & worldwide:  
<http://www.fda.gov/medwatch/report/consumer/consumer.htm>

UK medicines data, patient information leaflets (PILS) & full summary of product characteristics (SPC) on <http://www.medicines.org.uk>