Summary Report

(Completion rate: 73.96%)

# I have been diagnosed with chronic fatigue syndrome (ME/CFS)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| Yes |  | |  | 93% | 166 |
| No |  |  | | 7% | 13 |
|  | **Total Responses** | | | | **179** |

# I have been diagnosed with fibromyalgia

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| Yes |  | |  | 63% | 110 |
| No |  |  | | 37% | 64 |
|  | **Total Responses** | | | | **174** |

# My doctor prescribed Klonopin for me as a

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| Sleep aid |  | | |  | 66% | 107 |
| Calming agent |  | |  | | 41% | 67 |
| Other |  |  | | | 28% | 45 |
|  | **Total Responses** | | | | | **163** |

## My doctor prescribed Klonopin for me as a (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | muscle relaxer |
| 2. | Magic bullet! If I've overdone things my whole body feels out of kilter (wired, and more). Taking klonopin flicks me back to a more normal state and the next day I'm fine rather than in severe pain and exhausted. |
| 3. | brain protectant |
| 4. | IC |
| 5. | both sleep aid and calming agent |
| 6. | relief from excitatory neurotoxicity |
| 7. | to prevent crashes from overstimulation |
| 8. | to lessen severe hypoglycemic feeling, particularly at night |
| 9. | calming muscle contractions |
| 10. | gaba enhancer |
| 11. | Muscle relaxant and pain relief |
| 12. | restless leg syndrome and sleep |
| 13. | for neurotoxicty (hyper system, feeling wired etc) |
| 14. | Sensory overload surpressor |
| 15. | multiple reasons |
| 16. | muscle twitching |
| 17. | Restless Legs Syndrome |
| 18. | antispasmodic |
| 19. | ingling sensations |
| 20. | muscle spasms |
| 21. | IC |
| 22. | panic/blood pressure attacks |
| 23. | panic/heart rate control |
| 24. | Help with "Charlie Horse" spasms & sleep aid |
| 25. | 5 Years before ME for Cervical Dystonia |
| 26. | reduce muscle twitching during sleep |
| 27. | anticonvulsant |
| 28. | to prevent anxiety attacks |
| 29. | Lorazepam |
| 30. | restless leg and tinnitus |
| 31. | protect the brain |
| 32. | traozedone ,valium, triazolam |
| 33. | anxiety attacks |
| 34. | extremely jerky nervous system, extreme sensitivity to noise, motion, lights |
| 35. | stop muscle spasms |
| 36. | to treat severe muscle spasms |
| 37. | to treat severe muscle spasms |
| 38. | sleep aid and to lower neurotoxins. neurologist prescribes for "pre-seizure activity" |
| 39. | with xyrem, to help minamize the alerting effect of it as it wears off. It helps me continue in a deep sleep, after the deep sleep of xyrem wears off. I get more REM sleep using klonopin when taking xyrem. |
| 40. | Various, including: RLS, sensory overload, panic attacks, night sweats... |
| 41. | tinnitis, zapping sounds in brain |
| 42. | helps sensitivity to light and sound |

# The maximum dose of Klonopin I've used was

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
| .25 mgs/day or less |  | |  | | | | 8% | 12 |
| .5 mgs/day |  | | | |  | | 17% | 27 |
| 1 mg/day |  | | | | |  | 29% | 46 |
| 2 mgs/day |  | | | | |  | 29% | 47 |
| 3 mgs/day |  | | |  | | | 10% | 16 |
| 4 mgs/day |  |  | | | | | 4% | 7 |
| > 4 mgs/day |  |  | | | | | 3% | 5 |
|  | **Total Responses** | | | | | | | **160** |

# I've take Klonopin for

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
|  |  |  | | | | | 6% | 9 |
|  |  | |  | | | | 7% | 11 |
| 6-12 months |  |  | | | | | 4% | 7 |
| 1-2 years |  | | |  | | | 13% | 20 |
| 2-5 years |  | | | |  | | 18% | 28 |
| > 5 years |  | | | | |  | 53% | 84 |
|  | **Total Responses** | | | | | | | **159** |

# I take Klonopin

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | Percentage | Count |
| Daily |  | | | |  | 84% | 126 |
| a couple of times a week |  | |  | | | 6% | 9 |
| less than a couple of times a week |  |  | | | | 2% | 3 |
| intermittently |  | | |  | | 8% | 12 |
|  | **Total Responses** | | | | | | **150** |

# Klonopin has been

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
| very helpful for me |  | | | | |  | 58% | 90 |
| somewhat helpful for me |  | | | |  | | 22% | 35 |
| I have not noticed any changes |  |  | | | | | 3% | 4 |
| somewhat harmful for me |  | |  | | | | 4% | 7 |
| very harmful for me |  | | |  | | | 13% | 20 |
|  | **Total Responses** | | | | | | | **156** |

# I have been diagnosed with or exhibited signs of

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| tolerance (I have had to up my dose in order to get the same effect) |  | |  | | 29% | 46 |
| addiction (I have felt a craving for more Klonopin) |  |  | | | 8% | 13 |
| neither of the above |  | | |  | 67% | 107 |
|  | **Total Responses** | | | | | **159** |

# While you were taking Klonopin did you notice signs of 'tolerance withdrawal'? (Tolerance withdrawal occurs when you become tolerant to a medication and begin having 'withdrawal' symptoms without going off the medication -see the next two questions below for symptoms of tolerance withdrawal).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| Yes |  |  | | 20% | 31 |
| No |  | |  | 61% | 96 |
| I don't know |  |  | | 19% | 30 |
|  | **Total Responses** | | | | **157** |

# Please check any psychological symptoms that you experienced after you began taking Klonopin (These can be signs of 'tolerance withdrawal')

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | | | | | | Percentage | Count |
| anxiety (including panic attacks) |  | | | | | | | | | | |  | 57% | 37 |
| Depression |  | | | | | | | | |  | | | 43% | 28 |
| Insomnia |  | | | | | | | | | |  | | 48% | 31 |
| derealization/depersonalization (feelings of unreality/detachment from self) |  | | | | | |  | | | | | | 26% | 17 |
| obsessive negative thoughts (particularly of a violent and/or sexual nature) |  | | |  | | | | | | | | | 12% | 8 |
| rapid mood changes (including especially outbursts of anger or rage) |  | | | | | | | |  | | | | 38% | 25 |
| phobias (especially agoraphobia and fear of insanity) |  | | | |  | | | | | | | | 15% | 10 |
| dysphoria (loss of capacity to enjoy life; possibly a combination of depression, anxiety, and derealization/depersonalization) |  | | | | | | | | |  | | | 43% | 28 |
| impairment of cognitive functioning |  | | | | | | | | | | |  | 57% | 37 |
| suicidal thoughts |  | | | | | | |  | | | | | 28% | 18 |
| Nightmares |  | | | | |  | | | | | | | 18% | 12 |
| Hallucinations |  |  | | | | | | | | | | | 3% | 2 |
| Psychosis |  | |  | | | | | | | | | | 5% | 3 |
|  | **Total Responses** | | | | | | | | | | | | | **65** |

# Please check any new physical symptoms which you experienced after you began taking Klonopin. (These can be signs of 'tolerance withdrawal' if you have been taking Klonopin for several months)

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | | | | | | | Percentage | Count |
| sensory hypersensitivity (to sounds, odors, touch, taste, light..) |  | | | | | | | |  | | | | | 33% | 20 |
| Headache |  | | | | | | | | | |  | | | 40% | 24 |
| pain/stiffness |  | | | | |  | | | | | | | | 27% | 16 |
| tingling, numbness |  | | | | | |  | | | | | | | 28% | 17 |
| Weakness |  | | | | | | | |  | | | | | 33% | 20 |
| fatigue/flu-like symptoms |  | | | | | | | | |  | | | | 35% | 21 |
| muscle twitches, jerks, tics, tremor |  | | | | | | |  | | | | | | 30% | 18 |
| dizziness, lightheadedness, poor balance |  | | | | | | | | | | |  | | 42% | 25 |
| tinnitus (ringing in ears) |  | | | |  | | | | | | | | | 25% | 15 |
| double vision |  |  | | | | | | | | | | | | 12% | 7 |
| nausea, vomiting ,constipation, bloating, etc. |  | | | | | |  | | | | | | | 28% | 17 |
| flushing, sweating, palpitations |  | | | | | |  | | | | | | | 28% | 17 |
| urinary difficulties |  | | |  | | | | | | | | | | 15% | 9 |
| dry mouth |  | | | | | | | | | | | |  | 50% | 30 |
| Rashes |  | |  | | | | | | | | | | | 13% | 8 |
|  | **Total Responses** | | | | | | | | | | | | | | **60** |

# If you have stopped Klonopin please answer the following question...When I stopped Klonopin, I

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | Percentage | Count |
| Had no negative effects |  | | | |  | 36% | 28 |
| Some minor side effects |  | |  | | | 16% | 12 |
| Some moderate side effects |  | |  | | | 16% | 12 |
| Severe side effects |  |  | | | | 10% | 8 |
| Very severe side effects |  | | |  | | 22% | 17 |
|  | **Total Responses** | | | | | | **77** |

# If you stopped Klonopin please click the appropriate response(s)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| I withdrew from Klonopin under the care of the doctor who prescribed it for me |  | | |  | 91% | 51 |
| I withdrew from Klonopin using a specialist to help me get off it |  | |  | | 7% | 4 |
| I withdrew from Klonopin using a detoxification clinic |  |  | | | 2% | 1 |
|  | **Total Responses** | | | | | **56** |

# If you stopped Klonopin please complete the following sentence. "When I stopped using Klonopin I did" ( Please check all that apply. )

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| not use other drugs to help me withdraw from Klonopin |  | |  | 86% | 65 |
| use other drugs to help me withdraw from Klonopin. Please tell us which drugs you used. |  |  | | 18% | 14 |
|  | **Total Responses** | | | | **76** |

## If you stopped Klonopin please complete the following sentence. "When I stopped using Klonopin I did" ( Please check all that apply. ) ( use other drugs to help me withdraw from Klonopin. Please tell us which drugs you used. )

|  |  |
| --- | --- |
| # | Response |
| 1. | Tranzine |
| 2. | gabapentin |
| 3. | diazapam |
| 4. | dr. switched me to librium |
| 5. | panadeine,restavit,avanza,temazepan |
| 6. | benadryl |
| 7. | Klonopin @ d,when neededbecause it 'felt' addictive. take every nt for sleep |
| 8. | i used clondine (sp)Never stopped completely / severe shocks even 2mo's. on 1/8 mg. |
| 9. | i used clondine (sp)Never stopped completely / severe shocks even 2mo's. on 1/8 mg. |
| 10. | Ambien |
| 11. | Valium |
| 12. | Magnesium inj ections |
| 13. | I withdrew on my own |
| 14. | diazapam |
| 15. | Ativan |

# If you stopped using Klonopin please answer this question. How long did it take after you stopped using Klonopin for any 'withdrawl' symptoms you might have had to disappear?

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | | Percentage | Count |
| No time...I didn't have any withdrawal symptoms |  | | | | | | |  | 38% | 28 |
| About 1 week |  | | | | |  | | | 12% | 9 |
| 1-2 weeks |  | | |  | | | | | 10% | 7 |
| 2-4 weeks |  | | | |  | | | | 11% | 8 |
| 1-2 months |  |  | | | | | | | 3% | 2 |
| 2-6 months |  | |  | | | | | | 8% | 6 |
| >6 months (Please tell us approximately how long) |  | | | | | |  | | 18% | 13 |
|  | **Total Responses** | | | | | | | | | **73** |

## If you stopped using Klonopin please answer this question. How long did it take after you stopped using Klonopin for any 'withdrawl' symptoms you might have had to disappear? (>6 months (Please tell us approximately how long))

|  |  |
| --- | --- |
| # | Response |
| 1. | years |
| 2. | 18 months |
| 3. | 1 year |
| 4. | haven't tried |
| 5. | 16 months - ongoing symptoms |
| 6. | 7 months and had to restart it |
| 7. | Doctor told me not to stop |
| 8. | Years |
| 9. | 12months + |

# Please add any other comments here.

The 90 response(s) to this question can be found in the appendix.

# This benzodiazepine is

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | Percentage | Count |
| Alprazolam (Xanax, Helex, etc) |  | | | | |  | | 30% | 26 |
| Diazepam (Antenex, Valium, etc.) |  | | | | | |  | 33% | 29 |
| Lorezepam (Atvian, Temesta, etc.) |  | | | |  | | | 25% | 22 |
| Temezepam (Restoril, etc.) |  | | |  | | | | 11% | 10 |
| Triazolam (Halcion) |  | |  | | | | | 3% | 3 |
| Other |  | | |  | | | | 10% | 9 |
| Other |  |  | | | | | | 1% | 1 |
| Other |  |  | | | | | | 0% | 0 |
|  | **Total Responses** | | | | | | | | **88** |

## This benzodiazepine is (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | Clonazepam |
| 2. | diazepam |
| 3. | estazalam, Prosom |
| 4. | Ativan |
| 5. | Rivotril in Australia which is Klonopin in the US? |
| 6. | Oxazepam |
| 7. | codeine |
| 8. | Dilantin |

## This benzodiazepine is (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | zopiclone |

## This benzodiazepine is (Other)

|  |  |
| --- | --- |
| # | Response |

# My doctor prescribed this benzodiazepine for me as a

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| Sleep aid |  | | |  | 51% | 44 |
| Calming agent |  | |  | | 38% | 33 |
| Other |  |  | | | 33% | 29 |
|  | **Total Responses** | | | | | **87** |

## My doctor prescribed this benzodiazepine for me as a (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | control rise in heart rate during exercise |
| 2. | as before, magic bullet |
| 3. | adjunct to meclizine for Meniere's Disease |
| 4. | reduce spasms |
| 5. | excitotoxicity |
| 6. | Pain relief |
| 7. | muscle contractions |
| 8. | neuro-wired feeling |
| 9. | Muscle relaxant for pain |
| 10. | pain relief for spasms |
| 11. | temporary alternative to clonezapam |
| 12. | blood pressure/panic |
| 13. | periodic severe muscle spasm |
| 14. | for pain (fibromyalgia) |
| 15. | to use if I had an anxiety attack |
| 16. | anxiety |
| 17. | headache |
| 18. | used to treat fibro in early days |
| 19. | Panic attacks |
| 20. | stop painful muscle spasms |
| 21. | to relieve severe muscle spasms |
| 22. | muscle relaxant |
| 23. | RLS |
| 24. | Restless Leg Syndrome |
| 25. | short term ativan to get off Klonopin |
| 26. | don't know |
| 27. | muscle spasm, contractures |
| 28. | after lengthy protracted withdrawal from Klonopin. attempted to stabilize with valium and slowly taper off that- it backfired. |

# The maximum dose of this benzodiazepine that I took was

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | Percentage | Count |
| .25 mgs/day or less |  | | | | |  | | 19% | 16 |
| .5 mgs/day |  | | |  | | | | 14% | 12 |
| 1 mg/day |  | |  | | | | | 12% | 10 |
| 2 mgs/day |  | | | |  | | | 17% | 14 |
| 3 mgs/day |  |  | | | | | | 4% | 3 |
| 4 mgs/day |  |  | | | | | | 5% | 4 |
| > 4 mgs/day |  | | | | | |  | 29% | 24 |
|  | **Total Responses** | | | | | | | | **83** |

# I took or have taken this benzodiazepine for

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
|  |  | | |  | | | 16% | 13 |
|  |  | |  | | | | 10% | 8 |
| 6-12 months |  |  | | | | | 5% | 4 |
| 1-2 years |  | | | |  | | 18% | 15 |
| 2-5 years |  | | |  | | | 16% | 13 |
| > 5 years |  | | | | |  | 36% | 30 |
|  | **Total Responses** | | | | | | | **83** |

# I'm currently taking or was taking this benzodiazepine

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | Percentage | Count |
| Daily |  | | | |  | 52% | 43 |
| couple of times a week |  | |  | | | 13% | 11 |
| less than a couple of times a week |  |  | | | | 8% | 7 |
| Intermittently |  | | |  | | 27% | 22 |
|  | **Total Responses** | | | | | | **83** |

# This benzodiazepine has been

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| very helpful for me |  | | |  | 55% | 47 |
| somewhat helpful for me |  | |  | | 29% | 25 |
| I have not noticed any changes |  |  | | | 6% | 5 |
| somewhat harmful for me |  |  | | | 5% | 4 |
| very harmful for me |  |  | | | 5% | 4 |
|  | **Total Responses** | | | | | **85** |

# I have been diagnosed with or exhibited signs of

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| tolerance (I have had to up my dose in order to get the same effect) |  | |  | 92% | 24 |
| addiction (I have felt a craving for more of the drug |  |  | | 27% | 7 |
|  | **Total Responses** | | | | **26** |

# While you were taking this benzodiazepine did you notice signs of 'tolerance withdrawal ? (Tolerance withdrawal occurs when you become tolerant to a medication and begin having 'withdrawal' symptoms without going off the medications -see the next two questions for symptoms of tolerance withdrawal).

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| Yes |  | |  | | 17% | 14 |
| No |  | | |  | 71% | 59 |
| I don't know |  |  | | | 13% | 11 |
|  | **Total Responses** | | | | | **83** |

# Please check any psychological symptoms that you experienced after you began taking this benzodiazepine (These can be signs of 'tolerance withdrawal.)

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | | | | | | Percentage | Count |
| anxiety (including panic attacks) |  | | | | | | | | | | |  | 67% | 16 |
| Depression |  | | | | | | | | |  | | | 50% | 12 |
| Insomnia |  | | | | | | |  | | | | | 38% | 9 |
| derealization/depersonalization (feelings of unreality/detachment from self) |  | | | | |  | | | | | | | 25% | 6 |
| obsessive negative thoughts (particularly of a violent and/or sexual nature) |  | | | |  | | | | | | | | 21% | 5 |
| rapid mood changes (including especially outbursts of anger or rage) |  | | | | | |  | | | | | | 33% | 8 |
| phobias (especially agoraphobia and fear of insanity) |  |  | | | | | | | | | | | 8% | 2 |
| dysphoria (loss of capacity to enjoy life; possibly a combination of depression, anxiety, and derealization/depersonalization) |  | | | | | | | |  | | | | 42% | 10 |
| impairment of cognitive functioning |  | | | | | | | | | |  | | 58% | 14 |
| suicidal thoughts |  | | |  | | | | | | | | | 17% | 4 |
| Nightmares |  | |  | | | | | | | | | | 12% | 3 |
|  | **Total Responses** | | | | | | | | | | | | | **24** |

# Please check any new physical symptoms which you experienced after you began taking this benzodiazepine.

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | | | | Percentage | Count |
| sensory hypersensitivity (to sounds, odors, touch, taste, light..) |  | | | | | | |  | | | 26% | 9 |
| Headache |  | | | | | |  | | | | 24% | 8 |
| pain/stiffness |  | | | |  | | | | | | 18% | 6 |
| tingling, numbness |  | | | |  | | | | | | 18% | 6 |
| Weakness |  | | | | | |  | | | | 24% | 8 |
| fatigue/flu-like symptoms |  | | | | | | | |  | | 35% | 12 |
| muscle twitches, jerks, tics, tremor |  | | | |  | | | | | | 18% | 6 |
| dizziness, lightheadedness, poor balance |  | | | | | |  | | | | 24% | 8 |
| tinnitus (ringing in ears) |  | | | |  | | | | | | 18% | 6 |
| double vision |  | |  | | | | | | | | 12% | 4 |
| nausea, vomiting ,constipation, bloating, etc. |  | | |  | | | | | | | 15% | 5 |
| flushing, sweating, palpitations |  | | | | |  | | | | | 21% | 7 |
| urinary difficulties |  |  | | | | | | | | | 9% | 3 |
| dry mouth |  | | | | | | | | |  | 38% | 13 |
| Rashes |  | |  | | | | | | | | 12% | 4 |
|  | **Total Responses** | | | | | | | | | | | **34** |

# If you have stopped this benzodiazepine please answer the following question...When I stopped taking this drug, I

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| Had no negative effects |  | | |  | 48% | 24 |
| Some minor side effects |  | |  | | 14% | 7 |
| Some moderate side effects |  |  | | | 12% | 6 |
| Severe side effects |  | |  | | 14% | 7 |
| Very severe side effects |  |  | | | 12% | 6 |
|  | **Total Responses** | | | | | **50** |

# If you stopped taking this benzodiazepine please tell us how you did it

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| I withdrew from it under my doctors care |  | | |  | 90% | 28 |
| I withdrew from it using a specialist |  | |  | | 6% | 2 |
| I withdrew from it using a detox clinic |  |  | | | 3% | 1 |
|  | **Total Responses** | | | | | **31** |

# If you stopped using this benzodiazepine please answer the following question..... "When I stopped using this drug I did.... " (Please check all that apply.)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| not use other drugs to help me withdraw from drug |  | |  | 81% | 39 |
| use other drugs to help me withdraw from the drug. Please tell us which drugs you used. |  |  | | 23% | 11 |
|  | **Total Responses** | | | | **48** |

## If you stopped using this benzodiazepine please answer the following question..... "When I stopped using this drug I did.... " (Please check all that apply.) ( use other drugs to help me withdraw from the drug. Please tell us which drugs you used. )

|  |  |
| --- | --- |
| # | Response |
| 1. | Klonopin |
| 2. | back to Klonopin |
| 3. | Klonopin |
| 4. | My current psychiatrist preferred Klonopin; that's why I stopped Xanax. |
| 5. | Paxil |
| 6. | Klonopin |
| 7. | prozak, tiny dose |
| 8. | I started taking Klonopin |
| 9. | this was used to get off klonopin |

# If you stopped taking this benzodiazepine please answer this question. How long did it take after you stopped using it for any withdrawal symptoms to disappear?

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | | Percentage | Count |
| No time...I didn't have any withdrawl symptoms |  | | | | | |  | 51% | 25 |
| About 1 week |  | | | | |  | | 16% | 8 |
| 1-2 weeks |  | |  | | | | | 4% | 2 |
| 2-4 weeks |  | | |  | | | | 6% | 3 |
| 1-2 months |  | | |  | | | | 6% | 3 |
| 2 - 6 months |  |  | | | | | | 2% | 1 |
| >6 months. . Please let us how about how long it took |  | | | |  | | | 14% | 7 |
|  | **Total Responses** | | | | | | | | **49** |

## If you stopped taking this benzodiazepine please answer this question. How long did it take after you stopped using it for any withdrawal symptoms to disappear? (>6 months. . Please let us how about how long it took )

|  |  |
| --- | --- |
| # | Response |
| 1. | 1 year in and still tapering down - with ongoing side effects, sometimes fairly severe. It has been a horrible experience with no $ for detox and no end in sight |
| 2. | about 2-3 years |
| 3. | one year |
| 4. | I started taking Klonopin |
| 5. | ongoing after one year |

# Please add any other comments here.

The 42 response(s) to this question can be found in the appendix.

# Another benzodiazepine I have taken is

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
| Alprazolam (Xanax, Helex, etc) |  | | |  | | | 17% | 4 |
| Diazepam (Antenex, Valium, etc.) |  | | | | |  | 39% | 9 |
| Lorezepam (Atvian, Temesta, etc.) |  | |  | | | | 13% | 3 |
| Temezepam (Restoril, etc.) |  | | | |  | | 35% | 8 |
| Triazolam (Halcion) |  |  | | | | | 0% | 0 |
| Other |  | |  | | | | 13% | 3 |
| Other |  |  | | | | | 0% | 0 |
| Other |  |  | | | | | 0% | 0 |
|  | **Total Responses** | | | | | | | **23** |

## Another benzodiazepine I have taken is (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | generic Wellbutrin XL |
| 2. | Ambien |
| 3. | Codeine |

## Another benzodiazepine I have taken is (Other)

|  |  |
| --- | --- |
| # | Response |

## Another benzodiazepine I have taken is (Other)

|  |  |
| --- | --- |
| # | Response |

# My doctor prescribed this benzodiazepine for me as a

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| Sleep aid |  | | |  | 71% | 17 |
| Calming agent |  | |  | | 33% | 8 |
| Other |  |  | | | 8% | 2 |
|  | **Total Responses** | | | | | **24** |

## My doctor prescribed this benzodiazepine for me as a (Other)

|  |  |
| --- | --- |
| # | Response |
| 1. | muscle relaxant |
| 2. | anti-depressant |

# I took or have taken this benzodiazepine for

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
|  |  | | | | |  | 35% | 8 |
|  |  | | | |  | | 26% | 6 |
| 6-12 months |  | |  | | | | 4% | 1 |
| 1-2 years |  |  | | | | | 0% | 0 |
| 2-5 years |  | | |  | | | 9% | 2 |
| > 5 years |  | | | |  | | 26% | 6 |
|  | **Total Responses** | | | | | | | **23** |

# I'm currently taking or have taken this benzodiazepine

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| daily |  | | |  | 83% | 15 |
| couple of times a week |  |  | | | 0% | 0 |
| less than a couple of times a week |  |  | | | 0% | 0 |
| intermittently |  | |  | | 17% | 3 |
|  | **Total Responses** | | | | | **18** |

# This benzodiazepine has been

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
| very helpful for me |  | | | | |  | 43% | 10 |
| somewhat helpful for me |  | | |  | | | 17% | 4 |
| I have not noticed any changes |  | | | |  | | 26% | 6 |
| somewhat harmful for me |  | |  | | | | 9% | 2 |
| very harmful for me |  |  | | | | | 4% | 1 |
|  | **Total Responses** | | | | | | | **23** |

# While I was on this benzodiazepine I have been diagnosed with or exhibited signs of

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| tolerance (I have had to up my dose in order to get the same effect) |  | |  | 100% | 4 |
| addiction (I have felt a craving for more of the drug |  |  | | 50% | 2 |
|  | **Total Responses** | | | | **4** |

# While you were taking this benzodiazepine did you notice signs of 'tolerance withdrawal ? (Tolerance withdrawal occurs when you become tolerant to a medication and begin having 'withdrawal' symptoms without going off the medications -see the next two questions for symptoms of tolerance withdrawal).

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| yes |  | |  | | 14% | 3 |
| no |  | | |  | 76% | 16 |
| I don't know |  |  | | | 10% | 2 |
|  | **Total Responses** | | | | | **21** |

# Please check any psychological symptoms that you experienced after you began taking this benzodiazepine (These can be signs of 'tolerance withdrawal.)

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | | Percentage | Count |
| anxiety (including panic attacks) |  | | | | |  | 71% | 5 |
| depression |  | | |  | | | 43% | 3 |
| insomnia |  | | | |  | | 57% | 4 |
| derealization/depersonalization (feelings of unreality/detachment from self) |  |  | | | | | 14% | 1 |
| obsessive negative thoughts (particularly of a violent and/or sexual nature) |  | |  | | | | 29% | 2 |
| rapid mood changes (including especially outbursts of anger or rage) |  | | |  | | | 43% | 3 |
| phobias (especially agoraphobia and fear of insanity) |  |  | | | | | 14% | 1 |
| dysphoria (loss of capacity to enjoy life; possibly a combination of depression, anxiety, and derealization/depersonalization) |  | |  | | | | 29% | 2 |
| impairment of cognitive functioning |  |  | | | | | 14% | 1 |
| suicidal thoughts |  | |  | | | | 29% | 2 |
| nightmares |  |  | | | | | 14% | 1 |
|  | **Total Responses** | | | | | | | **7** |

# Please check any new physical symptoms which you experienced after you began taking this benzodiazepine.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | Percentage | Count |
| sensory hypersensitivity (to sounds, odors, touch, taste, light..) |  | |  | | 40% | 2 |
| headache |  | | |  | 60% | 3 |
| pain/stiffness |  | | |  | 60% | 3 |
| tingling, numbness |  | |  | | 40% | 2 |
| weakness |  | |  | | 40% | 2 |
| fatigue/flu-like symptoms |  | |  | | 40% | 2 |
| muscle twitches, jerks, tics, tremor |  | |  | | 40% | 2 |
| dizziness, lightheadedness, poor balance |  | | |  | 60% | 3 |
| tinnitus (ringing in ears) |  | |  | | 40% | 2 |
| nausea, vomiting ,constipation, bloating, etc. |  |  | | | 20% | 1 |
| flushing, sweating, palpitations |  | | |  | 60% | 3 |
| dry mouth |  | |  | | 40% | 2 |
| rashes |  |  | | | 20% | 1 |
|  | **Total Responses** | | | | | **5** |

# If you have stopped this benzodiazepine please answer the following question...When I stopped taking a benzodiazepine, I

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| Had no negative effects |  | |  | 76% | 13 |
| Some minor side effects |  |  | | 6% | 1 |
| Some moderate side effects |  |  | | 6% | 1 |
| Severe side effects |  |  | | 6% | 1 |
| Very severe side effects |  |  | | 6% | 1 |
|  | **Total Responses** | | | | **17** |

# If you stopped taking this benzodiazepine please tell us how you did it

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| I withdrew from this benzodiazepine under my doctors care |  | |  | 86% | 12 |
| I withdrew from this benzodiazepine using a specialist |  |  | | 7% | 1 |
| I withdrew from this benzodiazepine using a detox clinic |  |  | | 7% | 1 |
|  | **Total Responses** | | | | **14** |

# If you stopped using this benzodiazepine please answer the following question..... "When I stopped using this drug I did.... " (Please check all that apply.)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Response | Chart | | | Percentage | Count |
| not use other drugs to help me withdraw from it |  | |  | 79% | 15 |
| use other drugs to help me withdraw from the drug. Please tell us which drugs you used. |  |  | | 21% | 4 |
|  | **Total Responses** | | | | **19** |

## If you stopped using this benzodiazepine please answer the following question..... "When I stopped using this drug I did.... " (Please check all that apply.) ( use other drugs to help me withdraw from the drug. Please tell us which drugs you used. )

|  |  |
| --- | --- |
| # | Response |
| 1. | switched to Librium |
| 2. | Switched to another benzo |
| 3. | Alprazolam |

# If you stopped taking this benzodiazepine please answer this question. How long did it take after you stopped using it for any withdrawal symptoms to disappear?

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Response | Chart | | | | | Percentage | Count |
| No time...I didn't have any withdrawl symptoms |  | | | |  | 75% | 15 |
| About 1 week |  |  | | | | 0% | 0 |
| 1-2 weeks |  |  | | | | 0% | 0 |
| 2-4 weeks |  |  | | | | 0% | 0 |
| 1-2 months |  | |  | | | 5% | 1 |
| 2 - 6 months |  | | |  | | 10% | 2 |
| >6 months. . Please let us how about how long it took |  | | |  | | 10% | 2 |
|  | **Total Responses** | | | | | | **20** |

## If you stopped taking this benzodiazepine please answer this question. How long did it take after you stopped using it for any withdrawal symptoms to disappear? (>6 months. . Please let us how about how long it took )

|  |  |
| --- | --- |
| # | Response |
| 1. | years |

# Please add any other comments here.

The 16 response(s) to this question can be found in the appendix.

# Appendix

## Please add any other comments here. |

|  |  |
| --- | --- |
| # | Response |
| 1. | great survey! |
| 2. | I only took it a few times--it was TOXIC for me. |
| 3. | For me, this is something of a magic bullet - but if I used more than a few times a month I have a bounceback where it starts to cause anxiety. So self-limiting in a way. If I've overdone things my whole body feels out of kilter (wired, and more). Taking klonopin flicks me back to a more normal state and the next day I'm fine rather than in severe pain and exhausted. |
| 4. | I am a little confused here. I understand that benzodiazepines can be dangerous and addictive, and that there is definitely a built in 'tolerence' issue. I have found it very helpful to lower my dosage occasionally, and last year I took a medication holiday, so to speak. I do believe Dr Cheney is correct that Klonopin can be a brain protectant, but it must be used with caution in people who may have addiction issues. I also agree that 2-3 mg at night only is not good practice...lower dosages spread out during the day. As a sleep aid...I don't like that idea because we soon become habituated (it doesn't make us sleepy!) and then we are in a quandry. But I also think Ambien disrupts sleep in many ways. Tough call, huh? What works for me...smallest dose (0.5 mg 3 X's day) and stop/taper off periodically. This just happens to be what works for me. |
| 5. | I didn't go off the drug completely as indicated above. I just tapered down my dosage because of all the scary things I've seen posted here. I may eventually go off altogether, but for now this drug has really helped my over-reactions to food, chemicals, noise, etc. I guess I'm one of the lucky ones who has found this drug very helpful. |
| 6. | I did a slow taper down. I still have insomnia that nothing I've tried appears to help. |
| 7. | I took for a couple years. stopped to be in a study ( a year off ) then restarted and have continued on long term. Perhaps you should have something in your survey to reflect those who have taken "holidays" |
| 8. | 1 year into trying to gradually reduce dosage. it is VERY hard to do and the least bit of a slip up, weak moment of taking more to alleviate the withdrawal anxiety puts me farther back. a serious problem. |
| 9. | usual does is .5mg at bed; occasioanlly I take .125 mg during the day if I get an MCS exposure. I have never felt the urge to take more, or craved it in any way. |
| 10. | i've been taking 0.5 mg for sleep without habituation for over a decade |
| 11. | Klonopin has saved my life. It helps me cope with this awful illness. I take it only when I need it. |
| 12. | I have tried a ton of different meds and reacted badly to each one, but Klonopin was the absolute worst experience of them all. I stayed on it for less than a month because it was having such a horrible effect on my emotions and personality. |
| 13. | Very difficult to discern what is related to CFS symptoms and the various drugs, I have always been conscious of not becoming addicted to it so have used it sparingly. I have not had any dr's help in coming off this drug. |
| 14. | It does help short term, but builds problems, and now I only use it very rarely at very low dose .125 to tide me over a bad night. Not more thn a couple of times a month. |
| 15. | tapered down...didn't stop |
| 16. | I find that a larger dose (1mg) is very helpful for the PEM/tired & wired situation. |
| 17. | This is written by the mother of a man, aged 46, who had had ME/CFS for 20 years. Dr. Cheney was the second or third doctor who prescribed Klonopin for him and upped his dose to over 6 mg a day. Instead of alleviating my son's symptoms, it made them worse, although he would not admit that the exacerbation of his problems were at least partly due to Klonopin (he was also on high doses of Neurontin, also prescribed by Cheney). He became ever more depressed, so anxious that he said it felt as if "someone is always chasing me," saw no hope for a cure or substantial treatment for ME/CFS anywhere on the horizon - this was spring 2011. He committed suicide in June 2011. I blame the disease, Dr. Cheney, and Klonopin. Cheney was unresponsive to my son's problems and ultimately did not follow up with him at all. Why this and other "benzos" do not have black-box warnings on them, I can't fathom. |
| 18. | I take it during the day to enhance functioning: lower anxiety. |
| 19. | I took less than 0.5 mg. Klonopin at night to help me sleep. No problems. After 10 years I worried about dependence and got myself off it with only minor side effects. |
| 20. | I take Xanax (same working mechanism) 1mg twice a day, combined with 75mg Pregabaline twice a day. I'm extremely "neuro-wired" and it made a HUGE difference regarding light-noise sensitivity + suppression of that awful wired feeling. I really physically feel when it's time to take my meds. After about 8 yrs of taking these drugs I'm still at the same dosage. Simply the dosage I really need to temper my brain activity. To sleep I take gabapentine 100mg. AFter trying soooo many things it's the only thing that works well. |
| 21. | I was more depressed while using it. I tapered off very slowly, at a rate my body dictated, so I had little trouble. However, once off, I then had to find something else to help with my insomnia, so I returned to Trazodone, then added L-tryptophan too, which also helps with pain. |
| 22. | I was first prescribed this medication while in Rosamoff pain center as a way of getting off of opiates. I was on OxyContin and developed need of ever increasing doses. I was on 40 mg four times a day and felt very bad. I have been on clonazepam since then and also take Fioricet for headaches and Doxepin elixir 5mg nightly. This combination has been great for me or the past five years. It allows me to do a few errands in the mornings on good days and then take a nap and be able to cook dinner most f he ti |
| 23. | when I still could not sleep al night my doctor added 10 mg of elavil which has worked for me |
| 24. | i can tell u it is defently adicting, that why i only used as needed @ d |
| 25. | I had no help withdrawing and found a pharmacy to provide a compounded form so i could titrate down. The prescribing MD provided the prescription but he knew nothing about how to help me withdraw. it was dangerous and hellish. |
| 26. | The reason why I stopped Klonopin was it worked TOO WELL on the anxiety I previously had. Before it I had constant anxiety, while on it I was completely fearless (not feeling anxiety about anything)..so didnt fear any more things which one should fear. (so suicide attempts which I had BEFORE taking these drugs..well there was then nothing to stop me from suicidal jumping over a boucany as no fear at anything). This drug thou worked so so well for the ME/CFS things I got told it would help. Even less then the doses you have here in your tickboxes helped the ME wired with constant anxiety feel. |
| 27. | To sleep, I need to add a few drops of doxepin elixir sublingual along with Klonopin. Klonopin alone does not get me all the stages of sleep, and the wakings (alpha intrusions) still happen, but now I can sleep. My actual dose is 2.5 mg of Klonopin, which is not on your list. My sleep is still a problem (no regularity as when I sleep), but no other drug or drug combo had the least effect on my sleep once my body flipped from sleep all the time, to sleep never. If I go too long (over 30 hours) between doses, I get a mild headache now -- meaning I need to sleep, in my view. You survey is good, but your symptoms of going off Klonopin have high overlap with M.E. symptoms, making the list a bit confusing. Still sick, or reacting to going off the drug? Plus interesting to learn that inability to sleep /insomnia is a psychological symtpom, and not physical, as I view it. So I could not answer those two questions of yours -- I am still ill while taking Klonopin + doxepin in my search for sleep. |
| 28. | I seem to be able to skip doses without any problems except the initial symptoms I take it for coming back |
| 29. | One very appreciative benefit of taking klonopin was not ever having anxiety attacks. |
| 30. | It prohibits use of other meds that use the same liver enzyme. I am switching to Klonopin sub lingual. |
| 31. | I upped my dose to 1/2 mg, on it for 18 yrs. |
| 32. | I upped my dose to 1/2 mg, on it for 18 yrs. |
| 33. | I tried to taper off Klonopin for over 2 years using valium per Ashton's protocol...got way down to about .5 mgs, but doc refused to continue, put me back on klonopin, and I immediately needed 1.5mgs again to 'survive'. |
| 34. | currently in some sort of tolerance withdrawal. Consider it a HUGE mistake to use this drug long-term, even at small doses. I have a road ahead of me to try to get of of only .5mg/night with another .5 as needed. I avoided these meds for over a decade even though i had some panic issues b/c of fears, but they became a front-line treatment for CFS and I was RXed them by one of Teitelbaum's clinics. |
| 35. | I had a reduced dosage from 2 mg. to 1.5 mg. I am still on 1.5 mg. I only had about three days of symptoms. |
| 36. | I tapered off slowly over time. |
| 37. | Would like to stop altogether, but have only been able to reduce dosage significantly over a period of 3 years. Supplemented with high doses of GABA during reduction and still take hig doses of GABA doily. Was not given info on negative side effects/tolerance/addiction, etc. by first prescribing doctor. Found out the hard way! That was nearly 20 yrs. ago. |
| 38. | Klonopin helped me to sleep but the sleep was not refreshing, and I had a headache. I was aware of the fact that Klonopin could be addicting, and I wanted to discontinue it against my doctor's wishes. I did this by cutting back very gradually, but it was very difficult because of the severe craving and anxiety that I felt. My doctor kept telling me that this small dose was not harmful and that I should continue with it if it made me feel better, but I wanted something else that would not create that craving sensation that was so frightening. Eventually I got off it, and I tried a lot of other things. Another doctor helped me to find neuron tin which I took in liquid form and which worked and still works very well for me. It helps with both sleep and a lot of pain in my face that had developed. My sleep is refreshing. It took me 10 years to find this medicine. Also I take flexural 5 mg at night. The dosage of neuron tin is small also-still in liquid form but equivalent to 100 mg in pill form. I know that my first doctor saw me as a difficult patient, but I'm glad that I listened to myself rather than to him. He also refused to accept the fact that I was experiencing the pain of fibromyalgia. I have had CFS for 20 years so a lot has been learned since then, and hopefully this doctor has a different approach now. |
| 39. | Klonopin helped me to sleep but the sleep was not refreshing, and I had a headache. I was aware of the fact that Klonopin could be addicting, and I wanted to discontinue it against my doctor's wishes. I did this by cutting back very gradually, but it was very difficult because of the severe craving and anxiety that I felt. My doctor kept telling me that this small dose was not harmful and that I should continue with it if it made me feel better, but I wanted something else that would not create that craving sensation that was so frightening. Eventually I got off it, and I tried a lot of other things. Another doctor helped me to find neuron tin which I took in liquid form and which worked and still works very well for me. It helps with both sleep and a lot of pain in my face that had developed. My sleep is refreshing. It took me 10 years to find this medicine. Also I take flexural 5 mg at night. The dosage of neuron tin is small also-still in liquid form but equivalent to 100 mg in pill form. I know that my first doctor saw me as a difficult patient, but I'm glad that I listened to myself rather than to him. He also refused to accept the fact that I was experiencing the pain of fibromyalgia. I have had CFS for 20 years so a lot has been learned since then, and hopefully this doctor has a different approach now. |
| 40. | I have not tried Klonopin. |
| 41. | I tapered off by myself in an effort to reduce the number of RX drugs I take. |
| 42. | The most effective regimen for me was taking 4 meds at night, rotating them so that tolerance for any one of them did not build up. For whatever reason, only one doctor I went to thought this rotation was a good idea. I no longer have access to this doctor, and that sucks. |
| 43. | When I am well I only take .5 mg at night. When I am going through a bad patch I will increase it to 1 mg at night. I am always looking to taper it down as low as it can go.Sometimes I wonder if my evening headaches are related to "tolerance withdrawal' - waiting for my next dose. I have considered taking a long break from it, but I like sleeping. I use it in conjunction with trazadone (100-150 mg) |
| 44. | My doctor took me off 1mg of Klonopin, after being on up to 2mg at one point, for 14months. She did not titrate or use any other method to take me off of it. My doctor also increased and decreased my Prozac and Concerta at the same time. After about 6 weeks of severe withdrawl including a visit to the emergency room for an extreme anxiety attack, I switched psychiatrist to find some sort of relief. The new doctor stabilized my other meds and put me back on a dosage of .25mg of Klonopin 3x/day. I experienced the withdrawl for 8 weeks. It took about a week of being back on Klonopin for my body to stop experienceing all of the horrible withdrawl symptoms. I have now been back on Klonopin for 5 weeks and hope to be off of it one day. I feel that my body is dependant on it and that it does not help me with my CFIDS it only keeps the withdrawl from occurring. |
| 45. | I found a marked difference in generics particularly, Teva being + to Activis being- |
| 46. | Ive weaned my dose down, and felt more energy and clear mind. I used amino acids to help out, GABA, taurine and glycine. I did go too fast and had some pretty nasty withdrawals, so had to up it a bit to stabilize. I wanted to wean off completely, but life interrupted and I couldnt complete the process. Ive been on it 20 years. Ive learned that Klonopin puts you in stage 2 sleep, so you are not getting restorative sleep with it. So I am using low dose Trazadone for sleep now, which puts you in stage 3 sleep. So I am sleeping much better and using a cpap machine too, cuz I was having alpha intrusions. I believe some of the drugs Ive been on have made me sick. I also weaned off 10 years of Vicodin usage and my pain level dropped to not even needing tylenol at night. I quit Flexeril as well. Dropping 2 1/2 of my meds made me feel much much better. So, did 20 years of drug usage create 20 years of CFS??? I dont know yet. I need to get fully off the Klonopin when my life circumstances stabilize. |
| 47. | My answers above relate to Diazepam which I have taken for 40 years for M.E. Without it I would not have survived, yet still my G.P.'s are reluctant to prescribe it, saying it is not appropriate and habituating. I wish they suffered this devastating disease! |
| 48. | I stopped for a year--after 2 years on it ( to be in a study) and restarted a year later and have been on it for over 20 yrs total w/ no adverse effects. |
| 49. | I take Rivotril because I am Canadian and this is the commercial name for clonazepam |
| 50. | Am in the process of stopping Klonopin |
| 51. | My use of Klonopin was actually very short lived. It was prescribed to me primarily as a means of reducing my anxiety and panic symptoms, but all it did for me was knock me out cold for about 12 hours. When I awoke the next morning, I actually felt a sense of increased anxiety and an uneasy feeling or state of confusion as if I couldn't properly gather my thoughts or plan out tasks. I also felt not more fatigued, but weaker overall as if I had sucked the life right out of me. This was NOT unique to Klonopin, either. Because Klonopin is a long acting Benzo (12 hours), I was switched to low dose Xanax and the symptoms were nearly exactly the same. It appears to me that the entire class of Benzos affect me the same way with the only real difference being that I can take smaller doses of Xanax and the effects wear off a little faster. I now currently ONLY use a low dose Xanas when I am absolutely riddled with fatigue, pain, and insomnia and absolutely must get some sleep. |
| 52. | If I miss a dose I wake to slight seizures which are disturbing |
| 53. | if you withdraw at a SUFFICIENTLY SLOW pace, klonopin 'withdrawl' is no more difficult than withdrawl from any other drug. Withdrawing at 0.25 mg/10 days is a breeze. Sorry about your experience. Some doctors simply don't know what they are doing. |
| 54. | I wish I had never started taking it - I fear having to withdraw! |
| 55. | i attempted withdrawal 3 times. All three times my daily dose was at 1.5mg. I could not tolerate withdrawal symptoms and again commenced the medication. I have tried to reduce the dose to 1mg daily, but given i commenced potent treatments, such as anti-virals, anti-seizure and now Rituxan, withdrawal is not at the forefront of my treatment plan. I do hope to eventually withdraw from the medication given several attending MD's (over a period of 7 years) have commented on it's effect to potentially alter brain chemistry. I must also note that for 10 years i was mis-diagnosed and prescribed Klonopin as a "downer" to a panolpy of prescribed medications for numerous DX's. |
| 56. | I only took Klonopin for 2 weeks, I did it on my own, not with Physician. I know when I am having a problem. Worked well the first week-down hill after that.Too sedating. and began noticing I had to take more to sleep, I immediately increase Magnesium and started tapering my Klonopin. I now take Magnesium injections (given by myself) rec by my specialist. This take care of my sleep and I take 2 mg Valium when needed. |
| 57. | I've taken 0.5 mg for 18 years for sleep. If I feel tolerance building, I switch to xanex or Ativan for 3-4 nights. Then back to Klonopin. No problems |
| 58. | still withdrawing after 1 months usage |
| 59. | Many problems mainly interactions with other meds, eg analgesics, antibiotics. Tried to reduce very gradually. Got to 1.5mg and muscle spasm intolerable. Hate this drug. |
| 60. | The frequency of my anxiety attacks has been reduced. |
| 61. | once I stopped klonopin with no problems but then began again because I didn't sleep as well without it |
| 62. | I only took Klonopin ONCE - it made me stop breathing and I almost died |
| 63. | Even w a diagnosis I'd idiopathic hypersomnia, I can no longer sleep all night without 3 mg of klonopin. There have been occassional stressors that led me to take up to 2 additional klonopin. I cannot identify any neg. side effects other than dependence, which is negative enough. |
| 64. | I have taken it 3 different and each time was for 1 - 2 years. I very slowly tapered off of 1.5mg per day down to only taking .25mg/day for the last 3 or 4 weeks. Total weaning time was about 3 months. I used L-theanine the last 4 weeks during the day and added Melatonin at night. I was already taking Ambien at night which probably prevented some sleep withdrawls which might have lasted a week or so. I took 2mg of Xanax per day for 4 - 6 weeks and and a horrific experience getting of of it even with a very slow taper. My very well known CFS Specialist was the one that prescibed me the Klonopin the first 2 times I took it. |
| 65. | I believe I have developed a tolerence to Klonopin although I haven't increased my dose except for a quarter of a tablet on rare occasions. It's difficult to say whether some of the symptoms listed above are from Klonopin as they are common to CFS as well and I started taking it after having CFS. It has helped me a great deal for sleep and calming of nerve pain, etc. I "ran out" and had uncomfortable CNS effects and had to get a new script ASAP. I have been taking it 9 yrs. For these reasons I would like to taper off and stop the drug, but it is very helpful. I have noticed that when I have a healthier feeling day, I don't feel the need for the drug as much. |
| 66. | It's been great for "me" (CFS 28.5 yrs) Can't ever go over ones dosage; nor "never go off them" ~w/o "Dr P" Use only at bedtime. |
| 67. | To never have another anxiety attack because of klonopin has been such a blessing. |
| 68. | serious sucidal thoughts upon withdrawl |
| 69. | Klonopin (2mg) was a life saver for me. After 9 years we decided to slowly taper off over a 6 month term with no problems. |
| 70. | This family of drugs is TOXIC if you have a mitochondrial problem. Many CFS patients have mitochondrial problems and they need to avoid anything in the bezo family. This is known medical science. |
| 71. | I gradually decreased Klonopin on my own, a quarter of an orange pill at a time until my body had acclimated to that then I reduced it again. Did this until I quit. No adverse effects because so gradual. |
| 72. | Was not for me at all |
| 73. | I actually used diazepam, and took it prn so had no difficulty coming off it. Some years previously I was prescribed it for anxiety (pre-ME), and took 3 doses a day, initialy 2mg, increasing to 5mg, for several months, probably teh best part of a year if not more, and even then had no problems coming off it. I reached a point where I decided I didn't need it and just stopped taking it, with no advice, help or withdrawal effects. |
| 74. | My CFIDS has followed the cyle of remission/relapse. At some point I learned that the drug combination that worked for my sleep problems was Klonopin/Celexa/5-HTP taken every night. My last remission was so long ago (1994) that I may be mistaken but I do NOT remember any problem tapering off my drug regimen. I withdrew without anyone's help or supervision using a slow decrease of the amount of drugs over a month plus time. My last & final relapse was in 1996 and I restarted the above drug regimen shortly afterwards. Since the onset of CFIDS and the starting of Klonopin were so close together my selections in the two tolerance withdrawal sections could easily be due to CFIDS itself and not Klonopin. I'm happy to help you can contact me at major4579@yahoo.com |
| 75. | Don't remember exactly as it's been awhile. I've just recently started 1-2mg of Ativan for my Restless Legs Syndrom which has been helping me sleep a bit better. |
| 76. | I now take Klonopin only about once a week and that is for insomnia. I never take it more than that. |
| 77. | It is both a bad drug and a good drug - worked well initially, then had a lot of problems with it long-term |
| 78. | have muscular contractions at night, not simple insomnia |
| 79. | I went back on klonopin before w/d symptoms were finished. I feel the benefits outweight any "problems' so far |
| 80. | I actually didn't come complete off clonazepam. I cut down from 3 to 1 mg during about a 3 week period, and then went back up to the original dose because I was going to undergo a procedure for varicose veins and didn't want to have 2 things going on at once. Right now, I'm feeling pretty good, have taken a break from xyrem, and am ready to back down on the clonazepam again. |
| 81. | I suffer Gulf War Illness, caused by vaccines and aggravated by battlefield exposures. Most generic drugs cause severe adverse effects. There are no sleep aids to treat insomnia linked to GWI. Rare but very real heart disease has been misdiagnosed or mistaken twice for anxiety or sleep disturbance. Fixing heart disease has had no impact on severe insomnia. |
| 82. | I HAD to go back onto klonopin so am permanently on this now until MAYBE my other symptoms improve |
| 83. | I tried to taper but jumped out of my skin |
| 84. | physical symptoms listed...majority are experienced from M.E. |
| 85. | Due to withdrawal, I experienced flashes of light in my outer peripheral vision and "brain zaps". Dr switched me to Ativan since it was less addicting. |
| 86. | Klonopin is highly addictive and extremely difficult to withdraw from, with the potential for a painful protracted withdrawal. |
| 87. | Cort- your study really should have addressed benzos in general, not just Klonopin. But stopping benzos would mean several weeks difficulty falling asleep. Then it would be over. |
| 88. | I stopped KLonopin before a sleep study, then had light and sound sensitivity for at least 8 months, then read an article about Dr. Cheney recommending it, began Klonopn again to help my sensitivity to light and sound. I need it now to function. My withdrawal lasted so long (over 8 months) that I began it again. Hope to go off of it, but don't want the prolonged withdrawal again which renders me fairly unable to do anything. Now I can at least go out and take short hikes and be with people. |
| 89. | good med. never had withdrawal from it even after stopping it dead cold from 3>mg. sometimes would not take it for 6mos to a year then get back on it for a year(s) |
| 90. | still experiencing withdrawal effects i.e. spasms |

## Please add any other comments here. |

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| # | Response |
| 1. | I can't answer the max dose question because the only choices imply daily use and I take it once a week. |
| 2. | Lorezepam was as toxic to me as Klonopin. I would use these ONLY in a crisis. NEVER on a regular basis. They are the most TOXIC drugs I have ever taken. |
| 3. | Essentially, diazepam, zopiclone and clonazepam all worked much the same; changing occasionally helps reduce tolerance. Nb valium needs approx 10x clonazepam dose to get same effect.YOU CAN'T COMPARE MG DOSE BETWEEN DRUGS EASILY |
| 4. | I take Xanax .25 mg only when having Meniere's Disease attacks. It has helped the other medications--meclizine & prochloperizine--work better. |
| 5. | when i speak of withdrwal Sx, i mean those that occur after taking the drug for only one day! |
| 6. | I don't remember my course with Temazepam very well. I didn't use it every night as a sleep aid, but rather when I had really fallen behind on sleep. |
| 7. | I often go months without taking it, but when I need it, I take it. Not very often and perhaps one a day for a few days, then none for weeks or months. I've been taking it off and on for 15 years and have no desire to increase and totally forget about it until I definitely need it. |
| 8. | Thou I ticked the box, I havent withdrawn it under a doctors care as its still take it if i need it but I havent now needed it for 2 mths..so ticked that box as im not currently taking it and there was no other option there to tick. I take 15mg of this drug when needed (if my other sleep drugs are failing in which case I will be taking it 2 times per week (3 at most).. my doctor doesnt allow this drug to be taken more then this and even at that rate I build up tollerance to this (twice now)... Interestingly i dont build up tolerance thou to Klonopin when ive been taking Klonopin) |
| 9. | this survey should take into account that different benzos have different effective doses. Hence I started on 10mg and now would say 15 to 20mg is an effective dose, 20 years later. During that period I have come off it for a few weeks when I didn't seem to need it. Currently I do. I have never really been offered any advice on withdrawl form my doctor which is worrying. I cannot say for certain I have never had any withdrawl symptoms but if I have they have been not so different form ME fluctuations to notice. |
| 10. | 1-2 weeks was the most severe. Still had some low level symptoms for three montths |
| 11. | I have never taken this drug (diazepam, 1mg or 2mg per dose) for more than a week consecutively, usually a few days at most. I have thus avoided problems of tolerance/withdrawal. This is the reason why I only use this medication sparingly. |
| 12. | I used valium intermittently (maybe 10-20 times a year) to control chronic pain and spasms. 10 mg of valium at night would "unlock" me and I'd feel like I could operate normally the next day. No tolerance, no withdrawal issues. |
| 13. | I was only given another benzo as a substitue for clonexapam, then put back back on clonezepam. It was all the same. I have had no help in getting off clonexapm permenently. |
| 14. | I only took .5mg over a 2 year period less than 5 times. I took anywhere from .5mg -1mg about 5 times during a 2 week period when I was going through extreme withdrawl from Klonopin. |
| 15. | I've taken Xanax only under extreme circumstances and I've been on Klonepin |
| 16. | I completed the Klonopin comments and have taken Diazepam for 40 years the length of time I have had M.E. My husband also has M.E. and he takes Diazepam from time to time to help with neurological symptoms which are quite different to mine. |
| 17. | It works great for a couple nights and then not so much |
| 18. | Stopped on my own detox system using web reference |
| 19. | I diazepam 5mg prn severe back muscle spasm only |
| 20. | Take very rarely - when get Clonazepam withdrawal syptoms |
| 21. | Valium has a short life for me and I find I can take or not take to sleep. When my Magnesium doesn't do the job, I add the Valium. Never on it full time. I have no withdrawal for that reason. |
| 22. | I will take Klonopin as long as I need it - probably lifetime. I'm happy with it. |
| 23. | I understand that this is an addictive drug. It helps me with the anxiety i get from the CFS which I have had for 25 years. |
| 24. | I switched to 15 mg Mirtazapine at bedtime for a couple of years. Good to reduce headache and help sleep and relax. Have to withdraw slowly or head spining occurs. On nothing now. Have had ME since June 1990. Now 56 years old. |
| 25. | I withdrew 4 times, but within 3 days I had to go back on because I lost my balance due to muscle spasm |
| 26. | I felt like I was a better person on it...it finally went away. I was on it for 20 yrs. Could never go over the 3 mgs...made me feel weird. I stopped because a doctor i was going to thought I was addicted to it. |
| 27. | I was using it for anxiety and to help with rest and pain during the day. I decreased the dose on my own, then subsituted a tiny bit of Klonopin. I still have difficulty not taking a small amount of Klonopin .25 mg or less in the afternoon. |
| 28. | Prosom is a short acting benzo for sleep onset. It works well. I have no side effects except good sleep. I am addicted and will be. I need to sleep. I was on zanex..too strong. |
| 29. | This family of drugs is TOXIC for CFS patients with mitochondrial problems. It caused severe POTS and cardiac symptoms in me. I don't see those symptoms listed. |
| 30. | very dangerous and we are put on the wrong drugs |
| 31. | I initially took it 3 times a day but subsequently took it prn and had no difficulty coming off it - I just stopped taking it when I no longer needed it. Some years previously I was prescribed it for anxiety (pre-ME), and took 3 doses a day, initialy 2mg, increasing to 5mg, for several months, probably teh best part of a year if not more, and even then had no problems coming off it. I reached a point where I decided I didn't need it and just stopped taking it, with no advice, help or withdrawal effects. |
| 32. | Still using intermittently |
| 33. | Still effective & helps with sleep |
| 34. | Just started it 7/31/2012 |
| 35. | It works good but I'm afraid to try to get off of it. |
| 36. | I used Ativan to wean off Klonopin - difficult to tell which meds were causing all of the symptoms - seemed very much alike; have had to go back on both Klonopin and Ativan |
| 37. | I take the following combo for sleep: 21 mg melationin, 500 mg tryptophan, 20 mg doxepin, 350 mg Soma, 1 mg ativan: all at 11 pm, and then when I wake up 4 hrs later, I take 1 mg ativan and 175 mg Soma. This has given me my best sleep after 20 years of CFIDs. Still disabled with CFIDS, but able to to a little more. |
| 38. | I went back to using klonopin b/c of longer 1/2 life |
| 39. | I stopped completely and jumped out of my skin. I tapered off over 4 weeks |
| 40. | I notice the majority of the physical side effects listed are all affects of M.E., would be difficult for me to tell whether it was M.E., or the drug. I take 1.5 mg. of diazepam |
| 41. | Thanks for asking about benzos. They are the only really treatment PWCs have. |
| 42. | Spasms, spasms, spasms |

## Please add any other comments here. |

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| # | Response |
| 1. | it was not helpful for me. almost no effect |
| 2. | I only used Valium very rarely years ago, for situations like a long plane trip |
| 3. | .Valium was completely useless for helping my ME/CFS sleep issues so was stopped. |
| 4. | Used at different times and not concurently with temazepam. |
| 5. | Years ago, I once took it for 7 nights in a row, and had rebound insomnia for a few nights after that. So since then, I never take this for more than 3 nights in a row, and rarely need it that much. As a result, I haven't had any problems with it. The risk of addiction is why I only use it sparingly. |
| 6. | I have tried Xanax, not prescribed but supplied by a friend, and it was the quickest and best benzo for sleep for me; however, I know how bad the withdrawal is for it, so I've never even tried to get a prescription for it. I'll stick with my nightly 1 mg of Klonopin for sleep and hope it keeps helping, along with the 150mg of Lyrica at night. |
| 7. | I've been on 1.5 mg of Klonopin for over 10 years. My panic attacks are gone, my anxiety is under control, I do still have major Fibro flares. |
| 8. | I have tried more than 2 ! Have tried just about all. |
| 9. | Still taking with no ill side effects |
| 10. | this was used to get me some real sleep before putting me on alprazolam to stop muscle spasms throwing me over and help me sleep without stopping deep sleep like tempazepam |
| 11. | only used for about 2 weeks. Doctor cut me off at that point. |
| 12. | I returned to my 20mg Fluoxetine immediately to pull me out of the terrible feelings of despair I was having. |
| 13. | Used it in combination with Klonopin or as a rescue med for short-term procedures like dental work, MRIs |
| 14. | Because of gut malabsorption associated with GWI, I never enjoy full effects of pain meds or sleep aids. GWI gut problems include a plethora of vaccine-induced infections throughout the small intestine, so much so that no single antiviral, antibiotic, antiparasitic or antifungal will improve gut absorption. |
| 15. | Didn't help me sleep like it was supposed to |
| 16. | Sleep comes to me whether or not i take benzos. Just at the wrong times. I still work, so I must continue taking sleep meds, valium, to overcome the effects of CFS. If I were on disabilty I probably would not take benzos. It's a matter of being functional. |