

## Appendix 4

# HELPFUL TIPS FOR SURVIVING DRUG WITHDRAWAL

To best counter the effects of low dopamine, stay warm, stay well fed, be touched, listen to classical or familiar, well-loved music, and avoid crowds or anyone with an infectious illness.

### *Stay warm*

It is no coincidence that most PDers are diagnosed in the fall and winter. Dopamine is used in temperature regulation, and getting chilled can bring latent Parkinson's symptoms to the fore. Most PDers are chronically cold, with especially cold feet that simply do not respond to the normal sorts of warming treatments. About 10% go the other way – they tend to be overly hot. Dopamine deficiency can also create overheating, but this is less common. These people will want to stay cool during drug withdrawal.

During drug withdrawal, staying warm (or cool, if you run hot) is crucial. The caregiver may need to attend to this; the person who is in withdrawal will not be able to think clearly. By “stay warm,” I do not mean merely staying in a room that is heated to a comfortable temperature. Wear a hat at all times. Wear socks and slippers in the home at all times. Wear several layers of clothing. Wear something wrapped around the neck.

The human body needs to be approximately 98 degrees. The average home is kept at about 70 degrees. This difference is comfortable to a healthy person, but it can deplete dopamine in a person who is not functioning normally. A person who is in the throes of drug withdrawal has the same inability to regulate temperature as a person who is in the early stage of influenza – aches and chills can occur even in a well-heated room. Therefore, keep your drug reducer very warm, as if he was shaking with chills. A home hot tub or sauna can be very beneficial. A public spa is usually not a good idea; there is too much exposure to infection, and the stress of being out in public is counterproductive.

### *Heat*

During heat spells and the height of summer, the opposite may be the case. You may be utterly unable to deal with heat, and this may be more dangerous than the cold. Your body may not be able to figure out that it needs to sweat, and your pacing and shaking may heat your muscles to a dangerous degree when the ambient temperatures get close to body temperature. During heat waves, stay in cool, dark places. Go to an air-conditioned theater. Drink extra fluids, and take tepid baths. Put your feet in ice water. During times of unusually high heat, expect to feel as though you've been hit by a train.

### *Stay well fed*

Eat a lot. Eat starchy foods, filling foods, comfort foods. Keep your stomach topped up. Insomnia sometimes responds well to a completely full stomach. There are

## Appendix 4

neurons in the limbic system that saturate with neurotransmitters from either food or dopamine. If you keep these neurons filled from food, the scanty dopamine in the limbic area will go farther.

Staying full of food helps with insomnia. Insomnia is one of the worst symptoms, as it exacerbates all the other problems. Through experimenting, we've found that the following dinner menu ideas can be very helpful in allowing the drug withdrawer to get some sleep.

Start with a glass of wine or beer just before dinner. This may help calm you down enough to enjoy your meal. Eat plenty of starchy foods and rich creamy foods. Try starting with a nice cream soup or creamy chowder, followed by a hearty main dish such as stewed beef with potatoes or turkey with stuffing and gravy. Eat plenty of bread or buttered rolls. Be sure to eat dessert. Dessert should be something that makes your eyes roll back into your head – something with lots of butter or cream. Cake with thick frosting or pie a la mode is good.

If you normally drink alcohol with meals, be sure to indulge this habit. An after-dinner snootful, maybe a nice brandy or whatever you have in your locker, seems to add nicely to the mix. After a meal like this, you may feel almost able to lie down and get some rest for a change.

The quality of the sleep may not be perfect; you may need to burp a bit or take a digestive tablet if your stomach complains. However, this method of inducing sleep has been proven very successful in people who are otherwise unable to close the eyelids; somewhere between the salmon mousse and the avocado omelet, the brain starts to let its guard down.

Haggard, desperate reducers who haven't slept for weeks have found the food treatment remarkably effective. Often the idea of treating withdrawal insomnia with mere food is met with pooh-poohs. But when I call the scoffers the next morning and ask how they fared after a large meal, they often say that they slept well, or at least slept better than usual.

If you are able to digest dairy, don't be afraid to have a glass of warm milk at bedtime. If you can't digest dairy, consider a glass of something alcoholic. If neither of these appeals, try the white bread treatment. Several slices of white bread will temporarily convince your limbic system that all is well. You may need to repeat this treatment during the night, so keep a few slices of white bread on your night table, or a turkey sandwich waiting for you in the refrigerator. Don't think that you will have the presence of mind to put together a sandwich in the middle of the night. It will be hard enough for you to even remember that you made a sandwich specially for snacking on; when the frantic insomnia attacks, you can usually think of nothing except how horrible you feel. That's why the task of forcing you to confront the sandwich in the middle of the night may fall to the caregiver.

Turkey can sometimes be good for inducing sleep. Turkey contains sleep-inducing compounds. It works best if you eat plenty of warm turkey, with some starchy foods on the side. Again, this may seem far too simple, but it can be highly effective.

A high percentage of the PDers I've worked with do not drink alcohol. If a nightcap is out of the question, there are always milkshakes, topped with whipped cream. If both dairy and alcohol are forbidden you, try roasted potatoes with lots of olive oil. Keep some on hand, and heat them up at bedtime. Have extras to munch during the night.

They will work the best if they are heated before eating, so shove them in the microwave or quickly refry them.

Do not worry about gaining weight, especially if you have tremor or ticcing patterns. Most people with excess movement have to be concerned with losing too much weight. You can diet after you are done with the drug trauma. Keep your priorities straight. And if you do gain a few pounds, it is a small price to pay to be free of mind-altering drugs. The efficacy of the food method is seen in people who quit smoking – they often gain quite a bit of weight. This is because their body, denied dopamine, will reach out for the next best thing, and the next best thing is food.

However, when a person is getting off of really powerful drugs, such as cocaine, heroin, or the antiparkinson's medications, the mind is so twisted and battered that it cannot even think of food, it can only think of the drug. Also, the nausea and hypersensitivity to taste and smell during drug withdrawal can contribute to the poor appetite. Therefore, every inducement should be used to encourage a drug reducer to eat.

### *Alcohol*

Alcohol, when used to ward off symptoms of drug withdrawal, is usually safe and effective. Check with your doctor and your pharmacist to make sure that the drugs you are still using can be taken with alcohol. Do not use alcohol therapeutically if your doctor says not to, which he may if you have a history of intolerance to alcohol, liver or kidney damage, or any other reason that precludes alcohol use.

Alcohol, when used as a drug reduction therapy, is not addictive. This is because your dopamine levels are so low that the alcohol won't ever take you over the Safety Limit. As an example of this, consider the small drink of alcohol that is traditionally used, in some cultures, as the antidote for "next morning" hangover. Because of the crash from the excesses of the night before, dopamine levels will be quite low. By administering a "morning after" dose, a smallish drink of something alcoholic, the dopamine levels might rise up to where the agonies of the crash are lessened. As long as the morning-after dose is small, it will scarcely bring the dopamine levels up to a functional point; it will not exceed the Safety Limit.

Dopamine is not the only body function that is affected by alcohol; some of the pain of hangover is due to the dehydrating effects of alcohol and the damage that alcohol (a mild poison) does to various organs. I am not advocating alcoholism, or even a drink every night with dinner. I am presenting some information about alcohol because, based on experiences with drug reducing patients, it appears that alcohol can help subdue some of the more violent reactions of drug withdrawal, especially the insomnia. None of our patients became addicted to alcohol because of their alcohol use during withdrawal. Most of them scarcely noticed the effects of the alcohol in the traditional sense; their limbic centers were so stripped of dopamine that they never felt even a slight buzz from the alcohol. They did feel less frantic and paranoid, however.

It appears that alcohol is less addictive than the antiparkinson's drugs, the lesser of two evils, so to speak. I had two patients who felt strongly that they should not indulge in alcohol, even medicinally. I found it ironic that they felt that it was reasonable to take drugs that are much more powerful, mind-altering, and addictive than alcohol, because the drugs were sanctioned by the doctor. However, every person must decide for himself and feel good about his decisions. But I do note, again, that many patients have found

reasonably small amounts of alcohol to be extremely helpful in combating symptoms of drug addiction. None of them have been addicted or even drawn to alcohol after their recovery. Therefore, we do suggest that you might consider alcohol as an effective weapon in your battle with drug withdrawal.

### ***Massage and therapeutic touch***

If you are frightened of being touched, then massage will not be calming, so don't force yourself. But if you can feel comfortable getting a massage, do so, and be sure to tell your massage therapist that you need the room very warm and to go easy on the scented oils unless they are selected specifically for their calming effect. Gentle foot massage can be the least threatening of all the forms of massage, but some people prefer a shoulder massage or having their hair washed and trimmed.

Drug withdrawal sometimes responds to the touch of a living being. It can be a dog, cat, horse, or human. Sometimes, the worst paranoias of withdrawal are triggered by a sense of aloneness. Just having someone in the room is good. Having someone hold your hand is even better. Very often, if you are having trouble with freezing, a friend's hand on your shoulder can help you stay moving. It is very hard for most PDers to ask for help. This is your chance to grow up, and join the rest of humanity in admitting that none of us can go it alone. That "I am a rock, I am an island" stuff is what got you into this mess. Try reaching out for help or asking someone to hold your hand. You might be surprised at how willing we all are to help.

Some patients who are open to new ideas have found that New Age therapies such as aromatherapy and chakra balancing are beneficial. Find what works for you and do it.

### ***Mood***

Stay busy. Watch comedy videos and DVDs. Get dressed in the morning instead of lounging in your bathrobe. Most importantly, get out of the house.

"I don't want anyone to see me looking like this," is the defensive cry of the junkie who is crashing. But getting out and getting your mind off yourself is the best way to renew the influx of joy that makes the dopamine flow. We all give this advice to others when they are feeling miserable, but when it's a question of doing it ourselves we are more reluctant. Forget that you look haggard and weary, and too bad that you are tremoring – it's how you are. Your true friends will understand and the others can think what they want.

I hear PDers say over and over again, "I want to get better without anyone seeing me struggle, so that no one will ever know I had Parkinson's." This is sheer vanity, but it is especially common with this illness. It goes back to the original fear of letting anyone know that you are hurt. For those of you whose backs go up when reading this, who want to tell me that it is normal to hide weakness, let me say that this is not true. There are millions of people who, when they are hurt or sick, seek sympathy and help. You, if you have Parkinson's, probably dismiss those people (most of the people in the word) as weenies and weaklings. But they don't have Parkinson's now, do they. So, as you would recommend to others, get out of the house. Let people see you having a hard time, tell them about what you are doing, and be surprised at how they respond with compassion.

As for music, it has been shown that classical music and singing can cause a brain override that will allow movement in a person who is frozen in place from low dopamine

levels. I did an experiment with a patient who was frozen. We were at his apartment, and he was stuck in his bedroom doorway when I arrived; he had been there for half an hour. He whispered that he knew he wouldn't be able to walk until I arrived to help him. I didn't want to encourage this line of thinking, so I stood back and suggested that he sing. He pouted and said he didn't know any songs. He had been to a concert the night before: The Messiah. I told him to sing the Alleluia chorus. He laughed at the idea, but I insisted, and started singing it. Within two measures of him joining me in song, he was walking normally. He was adamant that it was my presence in the room, but twenty minutes later he got stuck again, struck up the chorus, and resumed moving. Music really does work to override the panic zone. Studies have shown that rock music is not particularly effective, and that classical or sing-along music is the best. A dark, silent house is a formula for paranoia. Keep the lights on and the music playing, and good food on hand.

### ***Stressors***

While getting out of the house and walking down to the mailbox might be a good thing, events that put you in the spotlight are probably a poor choice. Public speaking, running a fund-raiser, and these kinds of stressful activities may make you more edgy. You may wish to avoid this sort of thing. Many people find that they need to take time off work in order to take care of their health.<sup>1</sup>

If your great aunt drives you batty, or the grandchildren are going through a screaming phase, assert yourself. Don't have them over to the house, and don't go visiting even though your daughter wants you to babysit. You simply can't do all the things that you used to do, especially the things that made you grit your teeth.

### ***Acupuncture***

The NADA acupuncture protocol for relieving the stress of detox and drug withdrawal is highly effective. It is used in drug reform clinics with a higher rate of success than any other single method.

The protocol consists of needling five ear acupoints. In order of insertion, these points are: sympathetic,<sup>2</sup> Shen men, kidney, liver, and lung (either one of the two lung points). For pregnant women, the protocol is only three points: Shen men, kidney, and lung.

This treatment is done daily for several months or until the withdrawal symptoms begin to ebb. Usually it is done on alternate ears each day. The needles should be left in as long as possible. In some clinics, the needles are left in for an hour. In China, patients are often sent home with needles still in, and the patients can remove the needles several hours later, at their convenience. In the United States, because acupuncture needles are considered a medical device, and because they must be disposed of in special, red, medical waste containers, very few practitioners allow their patients to go home with the

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<sup>1</sup> Your health plan, disability insurance, and doctor will most likely not support you in this. Their attitude will be that you should just adhere to the current standard for medical care, which means take the drugs and don't make waves. You are on your own on this. Please do not write to me asking for some sort of note that you can give your boss so that he will give you time off or trigger your disability insurance. I do get these requests, and I am not in a position to answer them individually. This book is my statement.

<sup>2</sup> "Sympathetic" refers to the effect on the sympathetic nervous system, the system that pumps up the adrenaline during a time of crisis.

needles in place. Although several hours with the needles in can be helpful, most of the benefit occurs in the first fifteen minutes.

Sometimes, if anxiety or paranoia is present, it can be helpful to be needled at acupoints P-6 and Ht-7 as well. The acupuncturist should choose the arm that is trembling the least and observe the needles for several minutes to make certain that they are not going to be expelled by the trembling. These needles are left in for the more conventional half-hour to an hour. If confusion or lack of focus is more of a problem than anxiety, acupoints Yin Tang and Du-15 or Du-16 may be helpful.

### ***Know the nature of your challenge***

Know the difference between Parkinson's and drug withdrawal. Do not assume that everything that is bad is a worsening of Parkinson's disease. If you do, it will be easy to justify increasing the medication. After such an increase, there will be a return of all those symptoms that drove you to make a reduction in the first place. For example, suppose you reduced the meds because of ticcing, facial grimacing, or other symptoms of dyskinesia. After a few weeks, the anxiety, immobility, and shaking of drug withdrawal will make you look back with rosy glasses upon the dyskinesias. You may be able to convince yourself that the spasming wasn't so bad. But if you start taking the drugs again, sometime in the next few days or ten weeks, the violent ticcing, inability to swallow, or the facial spasms might reappear, together with the overly bright eyes and inability to think clearly, and your drug withdrawal work will have gone for naught.

Keep clearly before your mind's eye, or your caregiver's mind's eye, why you decided to reduce your medication. Only in this way can you hope to prevent seesawing back and forth between drug reduction and drug resumption. If you keep in mind just why you started the drug withdrawal to begin with, you may be able to keep a clearer head during the hellish withdrawal phases.

### **Antianxiety drugs and sleeping pills**

Our patients have gotten into serious trouble by accidentally abusing prescription antianxiety drugs or sleeping medications. These pills are valuable tools and can be very helpful if used correctly. However, most of them are extremely addictive and are only supposed to be used for a short period of time: a few days, not a few months. Here are examples of each.

#### ***Ambien***

Ambien, a sleeping aid, is recommended to be taken for no more than seven to ten days. It comes with a warning that patients may start hoarding it or self-overdosing, and it has a high risk of habituation and dependence. (These are more euphemisms for addiction.) If you need chemical help with drug withdrawal, which lasts for months, you might not want to take a drug which is addictive and which should not be taken for more than a week. Please note that the listed side effects of Ambien include depression, lethargy and "sleep disorder." From our experience, we have seen that one "sleep disorder" caused by Ambien is, surprise, insomnia. (Many of these drugs have side effects that are the opposite of the drug's intended purpose. Sleeping pills can, after several uses, cause insomnia; calming pills can eventually cause anxiety.)

### *Xanax*

Xanax, a popular antianxiety drug, is so addictive that, after prolonged therapy, the manufacturers suggest a 2 to 3 month gradual withdrawal period. “Prolonged” is not defined by the manufacturers. Based on our experience, “prolonged” is anything more than two weeks. Be aware that this drug is advertised as non-addictive.

Note these listed side effects of Xanax: tremor, confusion, insomnia, and nervousness. We have seen all of these side effects in patients who were prescribed this drug to combat their drug withdrawal problems. These side effects are not immediately apparent. They showed up after several weeks. By the time the side effects appeared, it was too late for our patients: they were addicted. Also, the listed side effects of tremor and nervousness will not necessarily go away; they are usually semipermanent.<sup>1</sup> If your withdrawal symptoms include tremor, nervousness, and insomnia, you may amplify all of your original problems by taking this drug.

### *Eli*

Eli had debilitating weakness and severe insomnia – he could never sleep longer than 5 minutes at a time. He found that his sleeping time extended to several hours when he weaned himself off Ambien. His doctor had prescribed Ambien because his sleep cycle was only several hours long. This short sleep cycle was probably due to Eli’s Sinemet. While Eli was taking the Ambien, his sleep cycle shortened to 5 minutes. He was terrified to reduce the Ambien, thinking that without it, he would never sleep again. When Eli finally got off the Ambien, his sleep cycle improved back to several hours, just where it had been prior to the Ambien. When he got off Sinemet, his sleep cycle lengthened further still. Over the months it lengthened to 5 hours a night and stayed at this level for over half a year until he died one night, in his sleep, of a massive stroke.

### *Family Counts*

Next, family members who do not know what is going on will not be helpful. Although the spouse, caregiver, or friend who is working closely with the patient might understand what is going on, the children may not. They may be furious. They may only want the parent or Old Friend to be “happy” again. When Hjalmar’s wife was so grateful to have her thoughtful husband back, the adult children were angry because daddy was looking less (mindlessly) cheerful. An outsider only sees the large motor movements or hears the loud voice. An outside observer cannot see the subtle changes in mental clarity and the subtle changes in motor skills. These outside observers will usually want mommy

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<sup>1</sup> Oliver Sacks proposed that the term “side effects” should not be used to describe symptoms that are set in motion by a drug which become permanent. He felt that the general understanding of the term “side effect” was an effect that a drug caused, and *which ceased when the drug was no longer taken*. The permanent and semipermanent damage caused by so many of these drugs is not a “side effect” in the traditional sense.

However, for reasons that are only too obvious, the drug industry continues to lump together both the short term and long term consequences of drug use. Actually, to be fair, the wording is changing. Although patients and doctors still speak in terms of “side effects,” the official drug company inserts and warnings use a new wording: “adverse effects.” I’m not sure what legal decision prompted this change of wording, but it still avoids the issue, which is warning patients that these adverse effects may endure even after the drug use is ended.

or daddy to just keep taking the pills. They will be understandably distraught that their crazy parents are not following the doctor's orders. This is often the most painful part of the process for the person who is trying to reduce medication. Nearly all of the patients who have Concerned Relatives say that the C. R.'s won't read any of the literature, they won't get involved, and they won't take the time to learn a little biology and/or chemistry and try to understand the complexities of what is happening. My feeling is that it is best to get the family on board before you even get involved in recovering. It is very hard to convince a family member that you are doing better if you are staggering through the throes of drug withdrawal. Over and over again with each 10% reduction, your family members will see you going into a pit of despair. And they will see that every time you finally start to feel better and to get your head above water, you will reduce meds again and go back down in the soup. They will fear for you. Help your loved ones to know what you are doing and why.

### *Summary*

Stay warm.

Eat very, very well.

Indulge yourself with massage or body work.

Keep your mood uplifted: get out and about, listen to music, sing out loud.

Avoid stressors.

Get acupuncture or whatever form of physical therapy is available and acceptable to you.

Keep a journal or some record to remind you why you are going through this.

Read carefully the warnings and adverse effects for any prescriptive drug that supposedly eases anxiety and insomnia; many of them will cause worsened anxiety and insomnia in the long term, plus they are highly addictive.