

Methadone Today

The official newsletter of DONT-BY PATIENTS, FOR PATIENTS April 2004 Volume IX Number III

Antagonist Drugs--A Lot Wiser

by Annette

I suffer from migraines, and I would say 85% of the time imitrex works. However, I had to go to a hospital the other day when the injection did not work. I have been using this small country hospital for years, and usually they gave me Demerol and Phenergan.

I had been warned about Nubain, Stadol, Narcan, and others I can't think of at the moment. Because I was most often given Demerol, I did not tell them about being on 99 mg of methadone daily. BIG MISTAKE.

The nurse told me she was giving me Nubain (10mg). My husband and I looked at each other and quietly decided to go ahead with the shot. BIG MISTAKE. You see, what I thought about being thrown into withdrawal instantly was not in my experience. What I had experienced before was a gradual onset of withdrawal symptoms.

Never in all my years could I have imagined what was fixing to happen to me. It took about 10 minutes for the burning on my back and the vomiting to begin; five minutes later, 15 minutes after the shot, I was in full ACUTE WITHDRAWAL SYNDROME.

There are no words in our vocabulary which can describe what ensued after. Apparently (my memory is not so good after the first 15 minutes) the whole ordeal lasted only about 2.5 hours to get me semi stabilized. I was given Vistaril first. When the doctor finally came (I swear it seemed like hours, but was only minutes), he looked at me and knew this was no picnic.

He told my husband that in his 20 years of practice he had never seen it that bad. He said he had heard of it but had not witnessed it. I was given an IV, then 2.5 mg of Valium, and a total of 22 mg of morphine, 2 mg at a time; then, about 10:30 p.m., he gave me Demerol. I was out cold at that time.

It started at 7:30 pm. He admitted me to the hospital until I showed no more signs of withdrawal for 4 hours. My husband and I left about 4:00 a.m. and, of course, went directly to the clinic at 5:00 a.m.

My God, I can't tell you how horrible it was; it was as if I was a rabid, wild animal (my husband's description). (**Cont p. 4**)

Faith-Based Treatment--My Bad Experience

by Laurie M.

I went to the Teen Challenge in Rhode Island in 1997 after a brief period in prison... I needed to find a place that would take me right out of court, as that was the only way the judge was going to release me. My ex-husband had friends who were involved with Teen Challenge, so they arranged for me to go there. The couple who took me there was very sincere; they were kind people, and I would never want them to think that I didn't appreciate their care, time and love for me, BUT it was a horrible disaster for me.

I arrived after court on a Thursday, and the first thing I was told was to throw out my cigarettes and medication (Prozac, Trazadone--anti-depressants). I knew this before I left jail but was so eager to get out that I would have agreed to anything at that point. Plus, I had tried every other type of program and was hoping that maybe this would work for me as I did have a strong faith in God. All I can say is that it was worse than jail. . . and I mean that, sincerely. The counselors and staff were all really dedicated and wonderful people who truly believed in what they were doing--two of the counselors were recovered heroin addicts from New York City, both had lengthy prison terms in their past, etc.--but the program drove me insane.

Typical day: get up at a.m. to shower, dress in DRESSES or skirts, and nylons, etc.; go to the chapel for a half hour for silent prayer; go to breakfast; go to 'classes' in the morning about the Bible, at 11:30; go back to chapel for an hour for a speaker and prayer; eat lunch; then spend the afternoon doing mailing and putting together brochures for Teen Challenge; back to the chapel at 4:30; then dinner; then out to church for 3-4 HRS!!!; Back to house; read Bible for half hour; then lights out. We weren't allowed to read any books but the Bible. We could only call once a week to approved people with a counselor listening!!!!, and we could write to and receive mail ONLY from approved people.

I just LOST IT THERE!! I got up Monday morning after actually lasting the weekend, and they told me it was a day of FASTING.... I went to the director and said that I wanted to leave. She really tried to talk to me about it and seemed to (**Cont. p. 3**)

Child Custody--Judges Should Rely on Medical Experts, Not Personal Beliefs

**Unfortunately, the author would like to remain anonymous*

Editor's Preface:

*In previous issues of **Methadone Today**, we have criticized judges that "play doctor", for example by requiring convicts on probation to withdraw from methadone.*

Recently, we corresponded with an individual who is presently involved in the legal system and had been a substance abuse treatment counselor and manager of substance abuse treatment programs--particularly in the context of the criminal justice system (counseling and managing treatment programs that treat inmates, parolees, or convicts on probation). In particular, he is involved in the oversight and of treatment programs contracted by the government to treat convicts diverted into treatment by the "drug courts". He has considerable education, training and experience in the areas of drug addiction treatment and the legal system.

Imagine a case where (1) custody is not contested by the other parent, the woman has been working a good program (i.e., no recent positives for any other drugs or meds), and she basically has "all her ducks in line"--meaning no recent criminal or other problems that might legitimately nix custody. But . . . say that the judge is an outspoken and well-known opponent of methadone treatment and s/he comes to the conclusion that as long as the mother remains on methadone, she cannot have custody of her child. Where will the child stay instead (presumably until the mother gets off methadone)? In the foster care system. One question is whether foster care is less risky (on all indices) than parents in recovery.

Another question is whether the judge's mandate--namely for the person to reduce her dose to zero--is, in effect, a condition of some kind of private court probation, a medical "prescription" made by a non-medical person, or a moral pronouncement? or is it a way to wrest decision-making from other public entities who the judge may have concluded cannot be trusted to "do the right thing"--or the judge's opinion of what the right thing should be in a given type of situation? (**Cont p. 4**)

Survey--Drug addicts prefer to be called "patients"

by Dr. Andrew Byrne, General Practitioner
(New South Wales, Australia)

**Does Anyone Care about Names? How Attendees at Substance Misuse Services Like to Be Addressed by Health Professionals. Keaney F, Strang J et al. European Addiction Research (2004) 10;2:75-79.*

At last somebody has asked drug addicts/users in treatment what they would like to be called. "Patients" is the consensus, at least in London. According to these authors*, the use of 'client' to refer to a patient dates back to at least 1970 when the nursing faculty at Wichita State University considered the term 'patient' inappropriate for the healthy seeking health-maintenance advice or going for an annual physical examination. The authors quote Wing: "The recent trend to refer to people seeking health care as 'clients' implies to me a component of human interaction that I would expect in the business world rather than in a trusting, helping relationship". 'Patients' also have a status and traditional rights which pre-date modern consumer laws.

In a survey of 150 mixed dependency patients, 'service user' was the least popular term, identified as the preferred term by only 5% of subjects. "Patient" was preferred by 66% of alcoholics, 52% of opioid users but only 47% of smokers in treatment. "Client" was only preferred by 24% of alcoholics, 46% of illicit drug users and 41% of smokers in treatment.

While only a minority considered that they personally had a 'mental illness' (38%), most considered that 'substance misuse problems' formed a category of mental health illness (59%). The authors state: 'Commonly used pejorative terms such as 'alki' or 'junkie' prejudice appropriate care and add to stigmatisation'.

Thus, the majority here preferred the term 'patient', going against current trends in dependency treatment services for the wider use of the term 'client'.

They conclude*: "In a culture of 'user involvement' in substance misuse, the results of this study should prompt reconsideration and revision of our verbal and written communications with patients".

Editor's Note: Virtually all patient advocacy groups--at least those advocating for individuals in opiate agonist treatment (i.e., methadone treatment)--strongly prefer the term "patient" over "client", and according to this survey, the majority of subjects would like to be called "patients". This does not seem to make a difference to treatment providers, at least in the U.S. Few treatment provider staff ever ask treatment recipients what they would like to be called. Perhaps treatment providers SHOULD ask what term the people they serve prefer.

Terminology: More at stake than personal preference

At least in the case of substance abuse treatment programs/modalities where doctors play a significant role in treatment, "patient" is the only accurate or correct term to describe the treatment subjects. It is especially difficult to understand why medical professionals would deem it appropriate to use the term "client" in the context of a treatment where medication is prescribed. And of course, in opiate agonist treatment (i.e., methadone treatment) the prescription/dispensing of medication is a main and necessary component of the treatment.

This issue goes well beyond what people in treatment would prefer to be called. There is a negative stigma attached to drug addiction, addiction treatment in general, and especially to opiate agonist treatment. This is certainly the case with methadone treatment and even LAAM treatment, though it remains to be seen whether the public is going to have such a negative perception of buprenorphine.

Use of the term "client" rather than "patient" to describe individuals in methadone treatment may add to the public perception that this is not really a legitimate addiction treatment. When the new federal regulations were passed, policymakers acknowledged that the public's negative view of methadone treatment could not be overcome until the treatment was placed more in the realm of mainstream medicine; but in mainstream medicine, people receiving treatment from a doctor are always called "patients".

Who knows what, if anything, most people make of the use of the term "client" to describe methadone treatment recipient. We are concerned that, at least in the minds of some people, this will reinforce the perception that methadone treatment is not really a medical treatment, but is instead a "harm reduction" measure. This view is that methadone treatment is similar to giving addicts a supply of drugs and fresh needles, and access to an injection room staffed with medical professionals in case of an overdose or emergency in order to minimize the harm associated with their addiction until they are ready to receive treatment and attempt to cease using these drugs entirely. These kinds of harm reduction efforts may help drug addicts, but they are not considered a 'treatment' for drug addiction--even if people see the value of harm reduction [which many Americans don't], such perceptions of methadone treatment further stigmatize methadone treatment.

We need to educate people that methadone treatment is an effective treatment for opiate addiction and not simply a harm reduction measure that, "substitutes one addiction for another,"--and using the term "patient" rather than "client" will at least put in people's minds the idea that methadone treatment is indeed a medical treatment.

Methadone Today would like to thank our Medical Advisory Board for their participation.

Our Medical Advisory Board includes:

Dr. Vincent Dole, Rockefeller University;
Dr. Marc Shinderman, Director/Owner of Center for Addictive Problems in Chicago;
Dr. Andrew Byrne from New South Wales, Australia, who has written two books about methadone and addiction;
Dr. Brian McCarroll, Director/Owner of Bio-Med in Clinton Township, MI;
Dr. Charles Schuster, Director of the University Psychiatric Center in Detroit, MI and former head of NIDA; and his associate
Dr. John Hopper, Medical Director of UPC.

It's Never Too Late

My name is Joey, and I am 38 years old. I have been addicted to opiates for about 15 years.

I started taking pain medication for an injury I suffered in the United States Marine Corps. I severed a nerve in my right hand and then developed a neuroma in the palm of my hand. Needless to say, I was in severe pain all the time.

First, I started taking Darvocet N 100, then Percocet, and finally Dilaudid. After about eight months of self medicating myself with these powerful painkillers, I was severely addicted.

Once the doctor found out about my abuse of the pills, he cut me off. That was when I had to hit the streets day and night to try and find these medications.

After a couple of years of this, I lost my wife, my kids, my home, my car. Everything that was once dear to me was gone.

After this, I moved out of state with my parents after being admitted to the hospital for severe withdrawal. It was then that my parents knew I needed professional help. I checked into a rehab, stayed the 30 days, and once I left, I went right back to using.

After three attempts in a rehab, I was still severely addicted to opiates. I started using Oxycontin and heroin on a daily basis but also tried to hide this from my parents.

Then I heard about methadone. At first, I really didn't know what to think; in my eyes, I was too far gone. My father took me to enroll in the program, and after a year of being on the long waiting list, I got the call and received my first dose of 30 mg. of methadone.

From that day forward, I've had a new lease on life. I've been in the program for one year and four months. I'm very proud to say that I haven't used in all this time. I have not had one positive urine or drug screen—not one.

My parents will say that without a doubt, methadone saved their son's life.

I now have six take home doses and go to the clinic just once a week. For anyone thinking of getting on methadone because of opiate addiction, please try the program. It worked for me, and I'm sure it can work for you.

Faith-Based Treatment (p. 1).

genuinely care, but after I kept refusing to stay, she told me that she would have to let my lawyer and the "authorities" know.

Meanwhile, a woman told me that the last girl in my type situation who tried to leave was taken by the Providence Police to jail to await the cops from Massachusetts!!

So, I went back into the director and told her that I felt that I should go to the chapel (it was the only room that had unlocked windows on ground level!) and pray about it. Well, I only prayed to get away--I opened the window and flew down the road. I only had a dime in my pocket, so I made my way to the bus terminal and begged a ride to Boston. End of story was with me back in Boston with a bag in my pocket in less than three hours.

As strong as my faith is in God, this type of program did the opposite for me. The services were Pentecostal. "People were speaking in tongues, being 'slain' by the Spirit," etc. . . which is fine if this helps someone and gets them on the right road. For me, it was frightening and more harmful than helpful.

I already had a HUGE amount of guilt over my addiction, and to be told that I was a sinner and that it WAS my fault just played into all my worst beliefs about myself. Let me say that I do believe that God can heal people of many diseases and that He does do it even today. What I don't believe is that God intended addiction to be singled out as the one disease that is a sin and that we should ignore the medical treatment we deserve because a few people within the Church have decided that we are sinners, not patients. I believe that God would want us to use whatever treatment is available to us, just as anyone does with heart disease, diabetes, and cancer. I get furious when people act like I should be "forgiven" for being an addict.

Oh, the plan was for me to stay in Rhode Island for four months, then be sent to some farm in Pennsylvania after that. I do believe that a lot of what they do is a type of brainwashing, and I guess to some people there could be worse things in life than being brainwashed by the Bible!

I hope that I made it clear that all of the people that I met there were kind, sincere people who really seemed to care for me and my welfare. I just don't agree in that type of treatment for addiction. Maybe, it would benefit some people who need to start over somewhere new with new friends, and if they have those type of beliefs, then it might be a wonderful experience for them. It just was NOT for me.

It was a rather crazy experience, like many others I had while active. I do believe that God saved me many times from bad situations. I was so naïve going into all this stuff that only God knows how I didn't end up dead or worse. I do believe there are worse things than being dead. Actually, active heroin addiction rates right up there.

The worst part about all of these programs for me was that it was one more failure, one more disappointment to everyone around me, one more time that I felt I WAS THE PROBLEM. It led me to such despair of ever being "OK" again. That's when all the thoughts of suicide or "accidental overdose"

would cross my mind as the only other alternative. I thank God every day (or almost every day, according to how the clinic is that day) for methadone being available to me. Certainly life is still there in all its tragic, boring, exciting existence, and I still needed to relearn a lot of things, but at least I was able to do that while on methadone.

Back to Teen Challenge. I went to a drugstore in town the other day, and there were two guys from Teen Challenge raising money for the program. They looked so cold and hungry (I remembered the fasting day), that I told them that my donation was to get them a coffee and a sandwich. They were ecstatic.

I talked to them while I was waiting for the bus. They were both heroin addicts who had gone into the program after trying everything else. Of course, they were two of the ones who had lasted. One was getting back with his wife and kids and was very happy. So, I guess it does work for some people and if it does, that's great. What I don't believe in is someone dictating what treatment will work for me and discarding any option that they don't agree with, such as methadone.

Every option should be available for all addicts, and all options should be discussed. Until I went to a methadone clinic, NOT ONE treatment program that I was in ever mentioned methadone as an option. It was always seen as a cop-out for those who weren't 'willing' to do the 'hard work' it took to get sober. It was considered a "failure" to go on methadone, so I never even considered it. It makes me angry to think of all the addicts who have died trying to get clean, never knowing that methadone might have saved their lives. I think all treatment programs that take federal or state money should be required to explain all options or, better yet, have patients from different programs come in to talk to patients. It would have saved me a lot of heartache and suffering had I known the truth about methadone years ago.

Editor's Note: One of the major problems we have with a "program" like Teen Challenge is that it cannot really be called "treatment" at all. In fact, the people that operate and work at such programs do not view drug addiction as a medical condition or disease. Oftentimes, the staff do not have any education or training in a field like social work, psychology, or medicine.

We find it very disturbing that they had her throw out her medication. Even IF Teen Challenge had a doctor there to make sure that stopping the medication would not do serious harm, there is something very wrong with their philosophy that ANY medication, or at least those prescribed to treat mental illness or addiction, is bad and should not be taken. Besides, the result of withholding medication may be suicide!

Child Custody (from p. 1).

Do all of these fall under the rubric of the court?

I agree with your assessment: Cases involving treatment and recovery in substance abuse cases or mental health conditions under treatment should be so identified for the purpose of the court then being able (required?) to request professional assistance in the assessment of the level of severity, the relative amount of risk to children, likelihood of relapse or recidivism, etc.

It also seems that there must be two separate processes: One for interpreting the mental state and psychological status of defendants and one for predicting the risks associated with returning a child to that defendant's care.

Can a judge who is not also a psychiatrist, psychologist, or clinically trained psychotherapist be expected to be able to recognize subtle differences between the rapid mood changes (affective lability) owing to Borderline Personality Disorder, active drug use, withdrawal from an addictive drug, or the fundamental fear a mother would feel in the presence of a powerful person in a black robe who holds the power--and has the will--to take or keep her child from her? As unbiased as judges need to have shown themselves to be to get that job, can any say that bias would not play a role in the interpretation of case facts where a client on methadone and child custody questions collide? For that reason alone, perhaps, judges might want to consider subordinating their interpretations of such symptoms to the counsel of experts. And where a judge has made his or her position known about an issue, such as the worthiness of a mother on methadone to receive custody of her child, wouldn't the ethical course of action be to defer to an expert's assessment--rather than run the risk of the appearance of bias clouding judicial judgment?

Of course there are other remedies, such as keeping up on the research. But to assume a judge with a fixed mind-set will seek new information that will contradict a long-held position is simply not reasonable. Judges don't have to take advice, nor do they have to challenge their own beliefs in light of the fact that they were already either elected or appointed in spite or because of them. So at what point in the process of a custody hearing, should the judge be asked to take a closer, more accurate, or more current look at the issues around something like methadone maintenance? If there is no "control" built into the process, then the idea that judges will review the state of their own understanding of an issue is not reasonable. Better, therefore, that a control mechanism be developed--wherein judges are more likely to seek expert assessment in prescribed areas where judges cannot be expected to maintain constantly updated expertise or truly meaningful, relevant, and current experience.

The fact that a judge has heard dozens of cases of a

certain kind--and always handles them the same way--does NOT mean the judge is an expert any more than information and knowledge are the same thing. Answering a question the same way over and over again will not make the answer correct if it is wrong. And consistently refusing to grant custody of her child to a mother on methadone does not make that stance right just because "I always do it that way." If the rationale for denying custody is based on anything but an expert's individualized assessment, built on current research, then a "verdict" against the mother may not be "just." On the other hand, not every mother--on or off methadone--is suitable to have custody of children.

But some way of determining who is and who is not likely to be a "safe and responsible" parent is critical to building a fair and unbiased process. And, needless to say, this applies to many other issues beyond child custody and methadone.

Antagonist Drugs (from p. 1).

I convulsed and purged out of every orifice of my body, but I was able to control my bowel because at the beginning, I could still walk and I went to the toilet. I jerked, I kicked, I vomited, I screamed--I was hot, then cold, then hot. I pulled my clothes off. My back would arch, my mouth would yawn so wide, and I would jerk forward. My legs and arms would stretch and extend way out (all out of my control). I hit people (accidentally), my body was on FIRE, my eyes turned yellow, blood pressure went crazy, and my skin was ice cold to touch, yet wet (my husband said). I felt like I was on fire, and I kicked uncontrollably; in fact, everything was uncontrollable. I remember grabbing my husband and saying, "I am still in here." I didn't look like me, act like me, and I could see it in my husband's eyes. I had to tell him I was still in my body. But I must say *me, myself* felt very small in my body; the rest was as if I was possessed. It was hell.

If you are taking methadone, please get medic alert bracelets or necklaces, or carry a card in your wallet with an alert in case you are ever in an accident (**to order a medical alert card from Methadone Today, see below**). Also, it is absolutely critical that everyone be honest and up front with hospitals, doctors, etc... regardless of how you will be looked at or treated, it does not compare to the way you will be looked at if you were to be given the wrong drug. Disgust describes it best. At least the usual looks are just disapproving. I know I will be okay; it's just so fresh right now.

Everyone must tell their doctors or hospitals the truth--no matter what. But most of all, never, never, never take any [opiate or narcotic] antagonist medication while on methadone. This cannot be stressed enough.

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