

Methadone Today

The official newsletter of DONT--by patients, for patients November 2003 Volume VIII Number VIII

Do You Know Your Rights?

By Kristi Wyatt, Recipient Rights Advisor
Parkview Counseling Center

As a Recipient Rights Advisor who works in a non-direct service capacity for a substance abuse outpatient methadone treatment program, the first question I am always asked is, "How can you be fair when you work for the company I'm filing a grievance against?" or "I don't want to get anyone in trouble," or "I don't want to be harassed." As a rights' advisor, my job is to investigate all the facts to determine if a recipient/consumer or patient rights have been violated according to title 42 Part 2 of the Code of Federal Regulations or otherwise known as 42 CFR. No patient should have a fear of retaliation as a result of filing a grievance, because this form of intimidation would be a violation of your rights.

Upon entering treatment, all recipients should be provided with a "Know Your Rights" pamphlet or literature on the rights' process. However, most recipients receive this information upon intake, and most fail to read it.

A brief overview of "The Know Your Rights" pamphlet:

As a Recipient/Consumer/Patient you have the right to know

1. how much the service costs and how much you must pay.
2. when violation of program rules could lead to discharge.
3. information on any drugs used in treatment.
4. if you or any information about you will be used in any research experiments.

YOU HAVE A RIGHT TO:

- # all civil rights guaranteed by state and federal law.
- # suggest changes in services.
- # expect the treatment center to look into your complaint.
- # help establish your own treatment plan.
- # to refuse treatment services and be told what will happen if you do.
- # talk with your own doctor or lawyer.
- # obtain a copy or summary of your patient record unless the program director recommends otherwise (if denied, you have a right to know why). (**Cont p. 4**)

Dear Methadone Today,

I enjoy the newsletter, and maybe you could point me to the proper people in my home state of Connecticut on these issues: methadone for men in prison and the clinics and prescriptions, as SOMETIMES the clinic resent some of us who get certain meds.

My prison stay in Connecticut was a trip in HELL. I was very ill, and both the judge and prosecutor agreed to put a note on my Mittimus asking the DOC (Department of Corrections) people to be aware of my illnesses. The DOC used the paper as toilet paper and had a good old time messing with me. First, I would end up with a regular guard making medical choices due to "security risk." In other words, there were times I did not get my seizure medications due to "security problems"? When I showed the Mittimus to them, they just ignored it by telling me there are no judges inside! This is just one example.

I came into jail on 125 mg methadone; plus I was taking anti-seizure meds for a recent injury where I hit my head on the back seat of a cab that got hit by a drunk driver as we sat on the side of the road. I was in lots of pain in my feet, plus I had a hernia. Well, the first four days in jail were the days they classify you. I was called "one of them crybaby junkies." The fifth day, it hit the fan, as finally my lack of doses kicked in, and I had ten plus seizures; they couldn't care less. If not for some great roommates, I would not be here today. I had five what they call "codes", so other inmates were now turning against me, as I was the cause for them missing TV time, since when I had a seizure, everyone got locked up, and they would lose free time. In this jail, you are in a two-man cell 22 and a half hours a day!

I was sent to the hospital 45 miles away twice, and I ended up faking killing myself to get some proper medical and mental treatment. I ended up in the looney bin, but I enjoyed the 24 hours alone where I could withdraw without hurting others or them coming after me. But when the big doctor showed up, it hit the fan, and I was sent packing, as I was not a mental health risk?

I was told men do not need methadone, as you DO NOT DIE FROM detox, plus the state could not afford the meds or treatment. Well, I cost the state thousands of dollars (**Cont. p. 3**)

Dear Methadone Today,



I am a new client on methadone maintenance. I just discovered your website after three hours of being online in hopes of finding a website that was actually "for" methadone. I cannot even tell you how many negative methadone web pages, articles, message boards, etc. I have come across, and I just can't believe this! Methadone literally saved my life and saved my three children from being motherless. I started out using Percocet and Vicodin due to gyn problems that were very painful. Then I started dabbling in morphine, Fentanyl, and eventually Oxycontin.

My "addiction" to opiates lasted roughly four years. In the beginning I could take one-half of a 40 mg Oxycontin and be "all set" for the day. Toward the end, I would have to chew two or three 80 mg Oxycontin to start. In order to stay high for an entire day, I would have to take that amount three times per day. The reason I'm telling you this is because I'm not sure if my case is different from most because I never used actual "street heroin"--never "shot

up", and it seems that I began to "lose everything", it was enough to make me smarten up—in four years—a lot sooner than most. I would cry all day because I didn't know what I was going to do or how I was going to get myself out of this mess. I had no idea there were detox centers for Oxycontin, not just actual heroin. I knew nothing of methadone for Oxycontin and little about methadone for heroin. Needless to say, because I am still alive, I ended up finding a detox center that used methadone and from there was put on methadone maintenance at a clinic in my hometown.

I can honestly tell you that methadone saved my life! When I was active in my addiction, I would sit and plot out how I was going to end my life because I saw no other way out of this mess. I have been on methadone for about six weeks now and have NEVER once "used". I know it's the methadone that is saving me because there was a six-day time period between the time I left the detox center and when I received my first dose of methadone at the clinic . . . I used every single day during that time period. I left the detox center and within two hours, I was chewing (**Cont p. 2**)

Dear Methadone Today (from p. 1).

an 80 mg Oxycontin. The detox center weans you off methadone so fast that by the last couple of days, you feel like crap because you are receiving 5 mg or 0 mg for the day. I feel that if you are transferring from a methadone detox center onto methadone maintenance, they should keep your dose up and give you take homes or something to get you through the week it takes to get on the methadone clinic. But either way, I made it through that week--not a very good way of doing it but I did. And like I said, I have been on the methadone clinic for about six weeks now.

I was tested the other day. I was at a home and using the rest room, and there on the counter was a big bottle of Vicodin. No one could see me, and there were lots of people at the house, so I could have gotten away with stealing some or all of the pills, but I didn't touch one! I used the rest room and went on my way.

I do not feel high from methadone; I feel "normal", the way I used to feel before I developed my addiction problem. I love it and would defend it to my dying day—it SAVED my life! And it stopped my three children—that I am raising alone, mind you—from being motherless and subsequently becoming wards of the state because they have no other family that would take care of them.

I am so happy to have found a website [yours] that feels the same way I do, and if there is anything I can do to help you with your purpose, just let me know. It really bothers me to see these people putting down my "lifesaver" with no grounds. For example, right before I found your website, I read an article named, "An Addict Against Methadone." She went on to say that methadone didn't help her but made her habit worse. . . well, come to find out, this woman was taking the methadone from the maintenance program in the morning to keep herself from getting sick and then still doing her heroin, etc. during the day and night. Her feeling was that the methadone, with its blocking effect on the heroin, caused her tolerance level to go up so her habit became larger due to the methadone! Have you ever heard anything so utterly ridiculous? Of COURSE methadone isn't going to work for someone who abuses it in that way! If you take your methadone the way you're supposed to, don't use, and let the methadone do what it's meant to do, it WILL work for you! Methadone literally saved my life and continues to save my life every day.

Thank you for listening and keep up the good work. **-Debra**

Dear Debra,

We are glad you found our website helpful. It is a common misconception that methadone treatment is only for heroin addicts. You may be surprised to learn that at a few clinics, the majority of patients had been addicted to prescription opioids, not heroin.

Obviously, we cannot comment on every website or article that is inaccurate. We have found many inaccurate, poorly researched articles regarding methadone treatment in newspapers or magazines that are supposed to be reputable and professional. And false, inaccurate, misleading, information is a much bigger problem on the internet generally. We believe the internet is a great tool, but it is a double-edged sword; there is a great deal of misinformation out there, so consider the source of the material.

As we have often repeated, advocates of opiate agonist treatment (i.e., methadone maintenance) have the facts on their side. The author of the article you mentioned is entitled to her opinion, but she is simply misinformed and wrong. So, what patients and patient advocates need to do is provide accurate education about opiate agonist treatment and opiate addiction. We also need to persuade treatment providers to do a better job of educating their patients. It is telling that plenty of erroneous information can be heard right in the lobby of many methadone clinics (e.g., patients' conversations).

Office-Based vs. Clinic-Based Treatment

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

**A comparison of buprenorphine treatment in clinic and primary care settings: a randomised trial. Gibson AE, Doran CM, Bell JR, Ryan A, Lintzeris N. MJA (2003)179(1):38-42.*

This trial of buprenorphine for heroin addiction has shown for the first time, to my knowledge, that agonist treatment can be given in primary care settings with results equivalent to those obtained in specialist clinics when patients are randomised at enrolment.

These researchers randomised 115 consenting heroin addicts who were seeking detoxification and offered them a 5-day course of buprenorphine in community practice or clinic practice. After two days without medication (days 6 and 7), they were given an option to transfer to maintenance therapy on day eight.

About 75% of patients returned at day eight, and one-third of them chose to have no further drug treatment. Of the other two thirds, all but four chose buprenorphine maintenance (two went onto methadone while another two chose naltrexone). It is to the credit of these researchers that of the 64/115 (56% of original group) who started maintenance, 40 (35%) remained in treatment at three months. This is a derived retention rate of 62% for continuing patients by my calculations.

There were no significant differences in any of the measures between the primary care group and the clinic group. Costs were also similar. The medication was administered in the doctors' offices for the primary care cases and at the clinic dispensary for the clinic patients during the detoxification phase (doctors are permitted to administer S8 drugs 'in the normal course of medical practice' as long as they comply with appropriate local legislative requirements for documentation, etc). For the maintenance phase, prescriptions were filled at community pharmacies where patients paid \$25 per week, contrasting with the clinics which were free of charge, making the outcomes for primary care even more impressive. There must be some doubt about some of the authors' derived conclusions regarding comparative costings owing to the necessarily approximate nature of the figures between private and public sectors.

The nature of this trial was rather unusual as it offered subjects the prospect of one thing (opioid detoxification) but ended up by giving most subjects quite the opposite (opioid maintenance). The rationale behind this 'ruse' was not discussed, although the consent included the possibility of maintenance if detox was not succeeding. It meant that although, by definition, all maintenance patients had 'failed' at their initial goal, their maintenance treatment was evidence based and very likely life-saving, unlike detoxification. Further, maintenance is, or should be, a flexible treatment which can be given by GPs and community pharmacists.

Editor's Note: This study appears to contradict claims made by many methadone clinics, that "clinics" which exclusively provide opiate agonist treatment provide superior quality treatment to properly trained physicians in a general office setting. In the U.S., the experience of numerous patients has been that office-based treatment is often superior to clinic-based treatment. There are some difficulties trying to apply the findings of this trial to the U.S., but policymakers should still take note: office-based treatment should be more widely available.

Dear Methadone Today (from p. 1).
in codes, rides, hospital visits, and seizure alerts where the nurses enjoyed the overtime, as they had to stay with me for a period of time to make sure I was okay. The nurses would really insult you, and the DOC staff had no compassion for anyone going through withdrawal.

I'm sorry, but no human being deserves to be tortured in jail. Yes, you break the law, you go, but then you must cover inmates' medical needs. In honesty, can you ask a man who is kicking 125 mg methadone to keep up with other men who are upset themselves and put two men in the same cell? And is it fair to either man? Once I was put in with a man doing life, as he was here for medical treatment, and he told everyone I was a dead man if they did not get me out of his cell. It took all my energy to get out of that only because a second shift supervisor agreed that match ups should be better and thought about; therefore, I was moved, and yet I thought I was going to die that day, as I was very sick and going to the open bathroom every five minutes, and this drove the lifer crazy!

If I was given a 20- to 30-day detox, things would have been better, and the state would have saved thousands of dollars. All you hear is budget this and budget that, and there right in front of them is a way to save a lot of money by just giving us a few cheap pills!!!

You have to ask, "Is it money, or do they like to torture men?" It really stinks that regular guards have to play doctor, judge and jury, as that is the truth behind the walls; you are at the mercy of your shift guard for eight hours, and then the next eight hours, all the rules change again. We call it "every eight new rules", as each guard brings his rules with him. It is HELL.

Also, sometimes when I get a prescription from a doctor, my counselor at the clinic plays doctor with it and me. I get morphine, as I have breast cancer and other serious medical problems. I get weird feelings from my so-called support system. "We can't tell if you are using." "You do not need it." "You don't look that sick." Jealousy and resentment also show up, and it changes the one-to-one counseling. We used to report to the nurse on this, and that was nice, as you could ask about interactions

and not get resentment answers, but now you report new meds to your counselor. This is how I feel, as it seems to drive a wedge between me and the clinic, and I don't like that, as I need all the help I can get "just for today."

Thanks for reading, and can you help me find the right people? Maybe I could help a little. **-CT Patient**

Dear CT Patient,

Thank you for writing in.

We agree with everything you wrote. The treatment of methadone patients in most U.S. prisons is appalling, but it is very difficult to get meaningful reform. The general public is not sympathetic to opiate addiction and certainly is not concerned with the plight of prison inmates. We had hoped that the couple of lawsuits (e.g., where an inmate who was refused their methadone dose died as a result, and the jail is sued by the deceased inmate's family) would pressure jails and prisons to change their policies concerning methadone, but this has not happened except for a few jails.

It is true that withdrawing from opioids rarely causes death, but some people have indeed died directly or indirectly from opioid withdrawal. However, it was the withholding of anti-seizure medications that put you at far greater risk. Aside from the

withdrawn from under careful medical supervision.

Different states have different regulations regarding prisons and treatment of inmates, and in at least some states, the state constitution may cover such issues. Under the current interpretation of the eighth amendment of the U.S. Constitution, which protects inmates from "Cruel and unusual punishment", inmates have very minimal rights regarding access to medical care. The prison may have violated your rights if they did not provide medical attention when you repeatedly seized. But unfortunately, you probably could not persuade a court that the prison violated your constitutional rights by withholding medication. We will cover this in detail in an upcoming issue of **Methadone Today**. Pre-trial detainees have greater constitutional protections, which we will also discuss in the upcoming issue.

You also complained about your clinic . . . how clinic staff hassles you about other prescription medications you are taking. This is a subject we have taken on in previous issues of **Methadone Today**. We strongly disagree with counselors "playing doctor" when it comes to what prescription medications you need or don't need. The only clinic staff that should even be discussing this with you is the doctor. We do understand why methadone clinics may want your other physicians to be aware of the patient's addiction history and the fact that they are currently on methadone maintenance treatment; a doctor may prescribe the patient medications, that s/he would not have prescribed had s/he been aware that they are on methadone maintenance treatment, etc. But assuming the patient has disclosed all relevant medical information to the prescribing physician, the methadone clinic should not give the patient a hard time or treat her/him as if s/he were using illicit drugs.

Many methadone clinics have used the argument that if you are prescribed opiate pain medications, "we can't tell if you are using opiates." On a drug screen, prescription opiate pain medications cannot be distinguished from heroin. For this reason, many methadone clinics will not allow take-homes for patients prescribed opiates on a long term basis. We do not find this argument compelling. Drug screens are just one tool used to assess a patient's progress in treatment; treatment providers should not rely on drug testing for this purpose exclusively. Despite what some clinic staff may say, there are patients with chronic pain who truly need long-term opiate pain medication. These patients should be accommodated, not punished.

PROBLEMS WITH YOUR CLINIC?

If your clinic is accredited by:

CARF, 4891 E. Grant Road, Tucson, AZ 85712, you may call toll-free **(866) 510-2273**

or **(866) 510-CARF**. This is a dedicated phone line for receiving consumer feedback during business hours. The number is TTY-

accessible for people with hearing impairments. www.carf.org

JCAHO Complaint Hotline, including requests for a Public Information Interview: (800) 994-6610 or complaint@jcaho.org

www.jcaho.org

probability of suffering brain damage, death, or other complications from seizures, withdrawal from the anti-seizure medications in itself could have killed you depending on what medications you were taking. As unpleasant as opioid withdrawal may be, withdrawal from certain other drugs (i.e., Xanax) is far more dangerous; phenobarbital, a barbiturate commonly used to control seizures, should only be

Your Rights (from p. 1).

YOU HAVE THE RIGHT TO EXPECT THAT A PROGRAM'S STAFF WILL NOT:

- ▶ abuse or neglect you.
- ▶ give out information about you without your permission (a signed release of information). [See the Editor's Note about a recent change to the law regarding disclosure of information.]
- ▶ require you to be part of any research if you don't want to.

YOUR RESPONSIBILITIES

- ▶ You are responsible for payment of your bill.
- ▶ You are responsible for knowing if your insurance company will pay for part or all of your bill.
- ▶ You are responsible for providing clear and accurate information about yourself.
- ▶ You are responsible for following rules of the program you attend.
- ▶ You are responsible for being considerate of the rights of others who are recipients of services or are staff.

"If you are in a hospital, halfway house, or other live-in setting, you have some additional rights" (See your Rights Advisor).

If you feel your rights have been violated at the program you attend, please talk to the rights advisor. If the problem can't be resolved with a simple mediation, then you can utilize the formal complaint process and request the "901" form.

Upon submitting your complaints to the rights advisor, your complaint will be investigated. You should receive a written response within 30 working days.

If you disagree with the investigative findings, you may appeal to the Regional Rights Consultant (you may contact your Program Rights Advisor or check the Recipient Rights Poster for the Regional Advisor in your program's area). The consultant will conduct an investigation and submit a written response within 30 days. If you disagree with the regional findings, you may appeal to the State Rights Coordinator.

Michigan Recipients Rights Coordinator
Michigan Department of Community Health
Center for Substance Abuse Services
320 A. Walnut, Lansing, MI 48913-0001

As a consumer of services, you do have rights.

*The above applies to **all** treatment programs.

Editor's Note: In regards to patients' rights to privacy and confidentiality, the law has recently changed. The new federal law

clarifies patients' right to have their information kept private, as well as requiring all providers of medical services to provide a handout to patients, "Notice of Privacy Practices," explaining exactly when patient records or information would be provided to third parties. We strongly recommend that you hold onto this literature, as well as other pertinent handouts you receive from treatment providers (i.e., paperwork provided to methadone patients at intake which contains information about the medication, the treatment provider's rules and policies, the facility's address, etc.); if you lost or threw away this material, you may ask the treatment provider for another copy of it.

Finally, the Rights Advisor for your treatment program should be listed on the "Know Your Rights" pamphlet or on the aforementioned poster. If you looked for/at the pamphlet and poster but could not find out who your Rights Advisor is, contact Beth Francisco (the Senior Editor of **Methadone Today**) by e-mail: bethfrancisco@netzero.net or phone: (810) 258-9064.

***POLICIES ON MMT--Jails vs. Prisons**

Note that jails tend to vary in policies and rules more than prisons. Some jails will medicate inmates and others will not. Jails that are willing to medicate inmates often depend on the treatment provider to bring the dose to the jail; however, this has caused problems in some cases where methadone clinics are closed on Sunday and are unwilling to deliver the Sunday dose--as generally, jails are unwilling to receive the Sunday dose on Saturday and hold onto it overnight (besides, it may violate federal or state regulations, depending on where the medication would be stored). A few jails will even commute the inmate to their treatment provider to dose. Jails may have policies which allow inmates to be medicated only under certain circumstances. Some states have laws regulating medical treatment of inmates in jail, but jails usually have a lot of discretion regarding specific policies.

Conversely, prisons are generally run by the state. A state agency, such as the "Department of Corrections" usually makes and enforces prison policies. Also a factor is that in most cases, prisons are reserved for convicts (pretrial detainees are usually held in jail)--most prison inmates are convicted felons and are being incarcerated for a significant period of time (6 months or more). Thus, prisons have more uniform policies than jails. Unfortunately, virtually no prisons in the U.S. provide methadone, even for a short term taper. Only Rikers' Island in New York provides methadone on a maintenance basis to some inmates.

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DONT is a non-profit 501(c)3 organization dedicated to helping patients achieve quality methadone treatment, preserve patient dignity, provide greater public understanding, eliminate discrimination toward methadone patients, and promotion of harm reduction policies.

Won't you please help us cover costs of the newsletter, web site, etc. **Your donations are tax deductible.**

IT DOESN'T MATTER WHAT OTHERS DO--IT'S WHAT YOU DO THAT COUNTS. PLEASE, do your part-- GIVE WHAT YOU CAN.

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