Quality Health Care Is Your Right!

A Guide for Drug Users to Getting Better Health Care

A PUBLICATION OF THE HARM REDUCTION COALITION
This booklet has been written for drug users in order to make going to the doctor and getting other kinds of health care easier.

It’s OK to be scared or nervous about going to the doctor.

Maybe you’re not sure what to say to the doctor. Or maybe you’re worried about what the doctor will tell you. Maybe it has been a long time since you’ve seen a doctor. Maybe you had a bad experience at a doctor’s office in the past. And maybe you just don’t like going to the doctor.

Stigma and judgment around drug use can lead to being treated differently by doctors and medical staff. Even though this shouldn’t happen—it can.

But there are lots of good, caring people working in health care who will care about you, your needs and your health.

Your health is very IMPORTANT!

You DESERVE good, quality health care—it is your RIGHT!

This booklet is meant to give you some tips that we hope will make getting good health care a little bit easier.

This booklet was written by Harm Reduction Coalition for drug users.

We acknowledge that some drug users face challenges when seeking health care. Our goal is to provide a booklet that drug users can relate to and learn from. Service providers and peers can use this booklet as a tool for starting honest conversations with drug users about health care. We’d love to hear what you think. Comments can be sent to:

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Why Go to the Doctor

Going to the doctor can be stressful. Doctors may tell you things you don’t want to hear. Going to the doctor can also be expensive. For drug users, there’s added stigma and fear of being mistreated. So, then why go? Here are some reasons:

- If you have an infection or serious medical problem it can get worse without medical care.
- If you have a long-term illness, it is good to keep track of how you’re doing. Knowing your options will help you make smarter treatment decisions.
- To get medicine.
- To stay healthy and to avoid future problems.

When to Go to the Doctor

If you have a problem or concern about your health, it is best to go to the doctor early. It is much easier to look for a doctor when you are feeling healthy.

- If you see a doctor when you don’t feel sick, you may be able to find a problem before it gets more serious.
- If your doctor knows you, you may get seen faster when you really need to or in an emergency.
- After you and the doctor get to know each other, it will become easier to talk about issues like drug use.
- By finding a doctor before you get sick, the doctor knows that you care about your health.
Where to Go for Health Care

• **Where are you already getting services?**
  Methadone programs, outpatient programs or other clinics may have health care services available.
  Places where you already get good services may know or be able to help you find good doctors.
  It may be easier to talk about drug use in places where you already get services.

• **General Health Care Clinics/Community Health Centers**
  Health care centers are good for *routine* care, and more serious things when emergency care isn’t required.
  You may be able to see the **same doctor** for each visit and you can often take care of many different medical needs in **one location**.
  Staff will get to know you and you may not need to give a detailed medical history each time.
  Some clinics will have a **sliding scale** for payment and/or take **Medicaid**. Community health centers must treat you even if you don’t have insurance.
  If you have internet access, find a health center near you at this link: [http://findahealthcenter.hrsa.gov](http://findahealthcenter.hrsa.gov).
  In NYC you can also call 311.

• **Hospital Emergency Rooms (ERs)**
  It is best to use the **ER only in an emergency**.
  If you’re having an emergency, ERs MUST treat people **even if they can’t pay**.
ERs are not designed for routine care—they are meant to take care of the most serious and urgent health care needs. Even though ERs may seem like an easy place to get general health care, community health centers will probably be able to help you more than the ER.

There can be very long waits because doctors need to be able to take care of the most serious emergencies first.

ER staff are often very busy. This may affect how they talk to you and the amount of time you spend with the doctor.

If you don’t have a primary care doctor or can’t go to a health center, the public hospital ER may be able to help you get rid of lice, scabies or other related pests.

- **Syringe Exchange Programs (SEPs)**

  Syringe exchange programs (SEPs) are places where you can get sterile syringes and other safer injection equipment. You can also dispose of your used syringes.

  SEPs work with drug users all the time. It is their job to be non-judgmental and to know about drug-related health issues.

  Some SEPs will have social workers, case managers or counselors that can help you to find services, make appointments, apply for Medicaid and other benefits, and even keep copies of important records. Some may even offer health care.

- **STI Clinics**

  STI clinics are places where you can be tested for sexually transmitted infections (STIs) including HIV.

  Some STI clinics also provide hepatitis C (HCV) testing.
Some clinics are free. At others you may have to pay a sliding scale for STI testing and treatment.

- **Mental Health Clinics**
  Mental health clinics have therapists, social workers, counselors, and psychiatrists to offer special help with mental health.
  
  It is important to **find someone you trust** when you talk about your feelings and emotions. If you don’t feel comfortable with someone, it is OK to ask to talk to someone else.

- **Immunization Clinics**
  Immunization clinics offer important vaccines for things like hepatitis A, hepatitis B, tetanus and the flu.

- **Infectious Disease Clinics (ID Clinics)**
  ID clinics offer special care for things like HIV/AIDS, HCV, STIs, and Tuberculosis.

- **Dentists**
  Good dental care is important to your health.
  
  Community health centers and some hospitals may have dental clinics or schools where **low cost** or **free** dental care is available.
  
  Find a dentist who will help you understand different **treatment options**. *For example, what are the benefits of getting a tooth pulled—or—what are the benefits of having a root canal instead?*
  
  Talk to your dentist about how much your treatment will cost and different payment options.
Paying for Your Health Care

Having health insurance **before you get sick** will mean more choices when you need them.

**Government health insurance programs:**

**Medicaid:** A program for New Yorkers who can not afford to pay medical care.

**Medicare:** A health insurance program for people over 65 or for people with certain disabilities.

**Family Health Plus:** A public health insurance program for adults who are aged 19 to 64 who have income too high to qualify for Medicaid.

**Child Health Plus:** A New York State health insurance plan for kids.

**HIV Uninsured Care Programs (ADAP):** A program to help people who are underinsured or have no health insurance to help pay for HIV/AIDS medications and primary care treatment. This may include payment of co-pays, deductibles and health insurance premiums. ADAP is not available to people with full Medicaid.

**NY Bridge:** A New York health insurance plan that allows people with pre-existing medical conditions who do not have insurance to buy it at a lower cost. People with alcohol, chemical dependency, and some mental illnesses are eligible.

Work with your case worker to see if you are **eligible** to apply for any of these programs.
If you receive health insurance, do your best to go to any meetings with your case worker and complete requests from Medicaid. It can be a problem if your benefits get cut off. You might even stop getting medicine that you need.

If you don't have insurance, look into public health insurance options and clinics that have a sliding scale for payment. You might be able to get Medicaid to pay medical bills you received while you were waiting for your Medicaid to start.

There is almost always a wait before health insurance (Medicaid or other health insurance) gets started.

• Medicaid and Managed Care Programs

Most NYS counties require individuals to choose a managed care plan to receive Medicaid benefits.

You may have 60 or 90 days to pick a managed care plan or else one will be picked for you.

When you pick a managed care plan, it means you must go to a doctor or clinic that is in that plan every time you need medical care.

Changing plans: In the first 90 days of being in a plan, you can change to another plan for any reason. After 90 days, changes can only be made for a few specific reasons.
• Medicaid and HIV Special Needs Plans (SNPs)

If you are HIV-positive, live in NYC, and get Medicaid, you can choose a managed care plan or an HIV Special Needs Plan (SNP).

An HIV SNP is a health plan that covers the same services as a Medicaid managed care plan, but also covers other special services that are important to people living with HIV.

When you choose a SNP, you will still have to go to a doctor in the plan. SNP doctors have a lot of experience treating people with HIV.

IF YOU LIVE IN NYC, YOU CAN CALL
1.888.692.6116 for questions about Medicaid
1.800.505.5678 NY Medicaid Choice

IF YOU LIVE OUTSIDE OF NYC, you can call your county Department of Social Services or visit: www.health.ny.gov/health_care/managed_care/index.htm

PROGRAMS THAT SERVE THE ENTIRE STATE OF NY

HIV Uninsured Program (ADAP)
1.800.542.2437 or www.nyhealth.gov

NY Bridge Plan 1.866.693.9277 or www.healthcarereform.ny.gov/preexisting_condition_plan/

Medicare 1.800.633.4227 or www.medicare.gov
Tips for Finding a Good Doctor/Provider

**Ask around:** Get referrals from other drug users, friends, family, co-workers, counselors, and people you trust. Find out what people like best about their doctor. Ask about strategies they’ve used to get good health care.

**Shop around:** Visit a couple of doctors. It might feel like a hassle at first, but in the long run, it is worth it.

Doctors at SEPs, methadone programs, and outpatient programs have experience working with drug users.

If you have a good experience at an ER, on a medical van or at an SEP, ask the doctors or staff there for a referral to a primary care doctor.

If you are not comfortable with a doctor, try finding someone new.

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**Remember, when you find a good primary care doctor or family physician, it will mean:**

More time to build trust with the doctor. This may make it easier to talk about drug use and sensitive issues.

Fewer visits to the ER.

Less waiting for medical appointments.

You may not have to give a detailed medical history at every visit.
Consider location: *How easy is it to get there? Are you comfortable going to a doctor in your neighborhood?*
You may be able to get many services in one location.
Ask your provider if you can get transportation costs to and from your visit.

Consider hours that the doctor is available or when the clinic is open: *Do the hours fit your schedule?*
Hospitals and hospital-based clinics may have more flexible hours, including evenings.

Make sure the doctor and her/his staff speak your primary language—communication is important!

Consider how you feel about the entire staff at the office or clinic you go to—they are all part of your health care.

You have a right to stand up for yourself and change doctors if you want to. Your medical records should not be shared without your consent (unless it’s an emergency).

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**Scheduling Appointments**

Schedule visits for a time when you are most likely to make it.

Find out if you need to make an appointment or if the clinic has drop-in hours.

If you ask for the first appointment of the day or the first appointment after lunch, you might have less waiting before you see the doctor.
How to Prepare for Health Care Visits

- **Think about your main reason for going to the doctor and what you want to get from the visit—stay focused.**

- **Take care of any drug use needs before the appointment.**
  
  Schedule appointments when you can be alert and won’t be in withdrawal. This will help you focus on the visit and won’t distract the doctor from the health care needs you want addressed.

  If you show up for your appointment too high, the doctor may ask to reschedule your appointment.

- **Make a list of questions you have for the doctor.**
  
  You may not get to ask all of your questions. Mark the questions that are most important to you.

- **Write down your symptoms.**
  
  Include what the symptoms are, when they started, how often you have them and how severe they are on a scale of 0 (no pain) to 5 (the worst pain you could imagine). Be realistic.

- **Make a list of medications that you are taking and other doctors that you are seeing.**
  
  Include prescribed medications as well as over-the-counter medicines, supplements and herbal treatments.

- **Bring someone with you when you go to the doctor.**
  
  It is good to have someone to keep you company, to help advocate for you.
• **Do your best to be on time (or even early) for the appointment.**

  Arrange transportation and/or money for transportation to and from your visit ahead of time.

  If you think you might be late or have to cancel your appointment—call the office as soon as you can.

• **Make sure you have your IDs and/or medical insurance card (if you have one) ready to bring with you.**

  It’s a good idea to keep copies of all of these documents.

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**Identification (ID) and Contact Information**

Most health care clinics will require that you have **one or more** forms of identification (ID) such as a state driver’s license or ID card, passport, military ID, etc.

If you don’t have or don’t want to give a **social security number**, it is better to say you don’t know it than to give a fake number.

**Even if you don’t have ID** or don’t want to give your real name or contact information, you will still be able to get some health care in the ER. **If you’re admitted to the hospital**, you should give truthful information for billing and medical record purposes.

There are many benefits to giving your right name and contact information. It allows the health care provider to contact you with important test results, if your medication needs to be changed, or if anything else important comes up.
What to Expect When You Get There

There may be a long wait.

- Try to plan ahead so you don’t go into withdrawal while you’re waiting. Bring something to do while you wait (something to read, crossword puzzles, etc).

- You can also use this time to think about and write down questions or things you want to talk about with the doctor.

You may talk to several nurses or other staff before you see the doctor.

- If you have to explain things more than once, be patient and consistent. Staff are there to help and want to hear information directly from you.

You may have to fill out some paperwork—it’s OK to ask for help, and to ask for paperwork in the language you understand.

Your time with the doctor may be short. Choose 1 or 2 of the most important problems to discuss.

Doctors are often busy.

It is not unusual for some doctors to answer the phone while you are with them.

- Even though it can be frustrating, doctors may treat you with more patience if you are patient with them.

You may be asked to talk about sensitive issues. If you need privacy, it is OK to ask for it.
You will be asked questions about your **medical history and current health**, including drug use (and the health of your family).

- Think about what you feel comfortable talking about so that you are not caught off guard.
- Doctors use this information 1) to help give you the right diagnosis and 2) so that they do not prescribe medication that is unsafe.

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**Talking about Drug Use with Health Care Providers**

Talking about drug use is personal. Even though it may not always feel like you have a choice, it should be up to you when and how much you talk about your drug use, even with doctors. Here are some things to think about when deciding how to talk about drug use with your medical providers.

- **Reasons why it may be hard to talk about drug use (and why some people decide not to):**

  You are concerned that doctors may treat you differently because of your drug use—instead of getting to know you as an individual.

  If you are a parent you may be afraid to tell the doctor because he or she might report you to child protective services for abuse or neglect.
You are afraid the doctors will focus only on your drug use instead of taking care of what you want help with.

You are afraid that some doctors prescribe medication differently to people who use drugs.

• **Some reasons why it is good to talk about your drug use:**
  
The doctor may be able to make a *better diagnosis* if he/she knows the whole story.

Even **symptoms** that may seem unrelated to drug use can sometimes be a result of drugs you are taking or the “cut” in those drugs.

There may be **interactions** between drugs you are taking (street, prescription or over-the-counter) and medications that the doctor wants to prescribe.

Being up front about your drug use can help *build trust* with your doctor. *Trust is an important part of your relationship and can lead to better care.*

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**IMPORTANT**

It is important to be honest with yourself about your drug use.

Try and find a doctor who makes you feel comfortable and respects your boundaries.

Doctors are not allowed to report your drug use to the police.
• **When talking about your drug use, it’s OK to build trust first:**
  If you need to—wait until the second or third visit to talk about your use.
  Be polite and keep an open mind—don’t expect the worst.

• **If the doctor is focusing too much on your drug use:**
  Politely remind them about the issue you are asking for help with.
  Ask the doctor to explain how your drug use is related to the issue you are asking for help with. If you disagree, explain this to the doctor in a friendly way—or find a new doctor.

**Here are examples of things you can say to the doctor when you don’t want to talk about drug use:**

“I hear what you are saying and maybe we can talk about my drug use later. Right now, I am more worried about _______.”

“I understand that you are worried about my drug use but I am not ready to change that. I still care about my health and would like your help with _______ now.”

“Can you explain exactly how my drug use will impact _______? I do want to feel better, and I don’t want to change my use right now. Maybe there are some other things I can do now?”

“If I can’t change my drug use right now, are there other things I can do to take care of my health? Maybe then we can start to talk more about my drug use.”
Tips for Communicating with Your Doctor

Your relationship with your doctor is important—it’s great when you can work as a team.

If doctors, nurses, or other staff don’t speak your language, you have a right to a translator.

Ask questions until you understand. It’s OK to ask for simpler answers. You have a right to understand your health care.

Be as honest as you can be. If you can’t talk about everything right away, it’s OK.

Be patient with your doctor—just as you want them to be patient with you. Remember that they are only human too and have good and bad days.

Stand up for yourself in a polite way. You can be firm, and still be friendly!

Trust yourself. If you think that the doctor is ignoring something important—ask questions. This can be hard, but in the end, your health is worth the extra effort.

Be careful about getting angry or defensive. Anger or aggressiveness will probably make the doctor stop listening and try to end the visit quickly.

You know best what will and will not work for you. Talk to your doctor if you think he/she is making an unrealistic plan for you. This is very important when taking your prescription medication.

Take notes or ask the doctor to write down important things for you.

Give positive feedback when things go well—let doctors know when they get it right!
Things that May Have a Negative Impact on Your Health Care

*Here are some things that might make doctors frustrated:*

- Answering your **cell phone or texting** during a visit. Think about turning it off or setting it to silent.
- Being **rude** or aggressive. **Even though things might get frustrating**, try to communicate in a calm and friendly way.
- **Missing appointments** without calling ahead or canceling many appointments in a row. It's OK to cancel, but calling ahead helps.
- **Saying that your pain is much worse than it is.** This can lead to the wrong diagnosis, getting more tests than you need, and it can take up more time. Being realistic and honest can help your relationship with your doctor.
- **Not getting tests** that the doctor schedules for you. If you can’t make it, let the doctor who scheduled the test know so that you can reschedule.
- **Telling the doctor what your diagnosis should be.** Give the doctor a chance to do his/her job. If you have had the same kind of problems in the past or you think the doctor is missing something, it can be helpful to share the information with them.
- **Selling your medication.** The medication was given to you to improve your health and if you don’t take it your health may suffer.

It is illegal to sell your medication. If the doctor finds out, he/she is responsible for reporting this and you could lose your insurance and even be charged with a crime.
Before You Leave and After the Visit

• **Schedule a follow-up appointment before you leave the office.**

Get the office to **write down the information on an appointment card** that includes the date and time of the visit. Also get the phone number and address of the office.

If you have a phone, ask the doctor’s office to give you a **reminder call** before the appointment.

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**IMPORTANT**

When you see a doctor, **ask for copies** of any test results, procedures, referrals or medications given. These are part of your medical record.

If you wait until later to ask for copies, they may be hard to get. You may be charged money and it can take a long time.

**Keep copies in a safe place** where you will be able to find them later. If you don’t have a place to keep them, ask someone you trust (friend, case manager, drop-in center, etc.) to keep the copies.

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• **If your doctor refers you to a specialist—it is important to follow-up.**

If things don’t work out with the specialist, go back to the doctor who referred you so that he/she can keep trying to help you.
• **Ask about potential side effects if you are given new medication.**
  Also ask if there are ways to make side effects easier to deal with.

• **After the visit, it can be helpful to make a list of things like:**
  
  *Dates of future appointments*
  
  *Dates of referral appointments*
  
  *Tests that were done to remind you to ask for results.*
  
  *Any new medications that you were prescribed.*
Tips for Taking Your Medicine

Get a pill case—the kind with a little box for each day of the week. They can be found at drugstores.

Many people have found that getting on methadone or buprenorphine is helpful when they need to take other medicines on a schedule.

Ask someone you trust to hold the medicine if you think you might lose it. They can also remind you to take it when you need to.

Find a pharmacy that is close to where you stay or cop drugs so it is easy to fill your prescriptions.

If you take street drugs every day, you could use coping as a reminder to take your medicine.

Talk to your doctor about your schedule (what time you wake up and go to sleep) and when it would be best to take your medicine.

Find out if your medication needs to be taken with food or on an empty stomach.

Ask the doctor what will happen if you drink alcohol while taking your medicine. It may not be a problem to take your medicine AND drink—it is better to ask your doctor than to stop taking your medicine. Some medicines (like some anti-depressants) will make you feel drunk faster though—so be careful.
Pain Management

**Pain affects everyone differently.** Pain is your body’s way of telling you something is wrong. It is often a sign that you need treatment to address the cause of the pain.

Doctors can be suspicious when a drug user says he/she is in pain and needs pain medication. They may think you are trying to misuse the medicine. On the other hand, experts tell doctors that they should never withhold pain medication when it is truly needed—so don’t give up hope that a doctor will help you.

Working with your doctor to address your pain can be a sensitive issue. You may need to negotiate with the doctor to make a plan that works for you and the doctor.

**HERE ARE SOME TIPS:**

**Keep a Pain Journal:** Write down when, where, and how much pain you have. Consider rating your pain on a scale of 0 (no pain) to 5 (the worst pain you can imagine). This will help your doctor to understand the level of pain you are in and help to track if the treatment is working for you.

- Record exactly how the pain is changing your daily activities. For example, is the pain keeping you from sleeping, working, or eating?
- Include a list of what you have done to help manage your pain, heating pad, over-the-counter medication, cooling the area, resting, etc.

If you do not want to take opioids because you are concerned about relapse or cravings, be honest with your doctor so that you can work together to think of other options.
Some ways that doctors treat pain may include:

- Diagnosing the **cause of the pain** and treating that condition.
- Discussing different **options** for controlling pain including stress reduction, physical therapy, acupuncture, as well as opioid and non-opioid based medications.
- Making more **appointments** to closely monitor your level of pain and medication use.
- Testing your urine for illicit substances.
- Recommending **counseling**.

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**Be Careful with Common Pain Relief Medicines!**

It is important to talk to your doctor if you are taking Tylenol (acetaminophen). **Acetaminophen can be more serious than you may think**...and it is common in many cold medicines and pain medicines (Percocet, Vicodin, Ultracet, etc.).

Too much acetaminophen can cause **very serious liver damage or liver failure**. That means no more than 8 tablets of Extra-Strength Tylenol a day (4 grams or 4000 milligrams) and be careful when you take it every day for a long time.

If you have hepatitis B or C, you should talk with your doctor about acetaminophen. The general rule is to avoid taking more than 2000 milligrams per day.

*Drinking alcohol on top of high doses of Tylenol can be damaging to your liver.*

Ibuprofen (Motrin, Advil) and Naproxen (Aleve, Midol) should be taken with food to avoid stomach ulcers.

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Pain management is really important to your overall well-being. It can take time to get pain under control so having a trusting and ongoing relationship with a doctor is important.
Methadone

Tell your methadone clinic or doctor if you start taking new medication. Some medicines can make your body process methadone slower or faster, meaning your methadone dose may need to change if you start taking new medications.

If you are on methadone, you may have been told that you cannot take “Talwin.” This is true, but you should also know that Talwin is not used much anymore. So, if you tell a doctor you can’t take it, you are basically telling them that you are on methadone.

It is important to talk to your methadone program about medications prescribed to you—especially if they might come up in your urine. Bring the bottles to your appointment if you can.

Reproductive Health and Pre-natal Care

It is important for women to visit the obstetrician/gynecologist for regular exams—even if you are not getting your period.

If you are pregnant and using drugs, prenatal care including HIV testing and hepatitis B testing is VERY important for your health and your baby’s health. If you find out that you have HIV or hepatitis B, there are things you can do during pregnancy to reduce the chance of your baby getting it.

If you are pregnant, strongly consider getting into drug treatment.

Pregnant women usually go to the top of the waiting list for drug treatment.
HIV and Hepatitis

- **HIV/AIDS**: If you are HIV-positive or have AIDS, it is best to find a provider who has experience working with people with HIV/AIDS. They are more likely to have up-to-date information on medical treatments.

  It is very important to take HIV medicines **exactly as they are prescribed**. If you do not, the virus can figure out ways to make the medicine stop working (called resistance).

  There is **public assistance** (including medical insurance) for people living with AIDS in New York State.

- **Hepatitis C (HCV)**: Anyone who has **ever** injected drugs (even once) could be at risk for HCV.

  There are different kinds of tests for HCV. It is important to understand what kind of tests you are having done.

  Antibody tests can tell you if you have **ever** been infected with HCV. But it is possible to have a positive antibody test for HCV and to **not actually have HCV infection anymore**. Ask your doctor for more information.

  Everyone who tests positive for HCV antibodies should have **additional tests** to see what your current HCV status is.

  There are **medicines to treat HCV**, but not everyone with HCV needs them. Ask your doctor for more information.
Some drug treatment programs have medical care on-site.

There are many different kinds of drug treatment programs, both inpatient and outpatient.

It is important to find a drug treatment program that will support your needs. Try and find out exactly what kinds of groups and services are offered.

Calling programs before you go can give you a better idea of what to expect.

Find out what kinds of drug treatment your insurance will cover and how often they will cover it. For example, if you leave a 28-day program early, you may not be able to go back again for a certain period of time.

Some programs will be able to help you with medical detox and some will not.

Ask your provider for help finding the treatment program that will best meet your needs.
Mental Health

If you are thinking about hurting yourself, go to the ER or call 911.

**Mental health services**, like counseling or getting medication, can be accessed at some syringe exchange programs, community-based organizations, community health centers, and the ER.

If you are waiting for your Medicaid or insurance to kick in, ask your psychiatrist if they can get “samples of medication” or help with **patient-assistance programs** (drug company programs where they give medication to people who need it, but can't pay for it).

If you take benzos (like Xanax, Klonopin, Librium, etc.), be very careful when you stop taking them for a period of time. **Coming off benzos too fast may cause medical problems, such as seizures.**
The Harm Reduction Coalition is a national advocacy and capacity-building organization that promotes the health and dignity of individuals and communities impacted by drug use. HRC advances policies and programs that help people address the adverse effects of drug use including overdose, HIV, hepatitis C, addiction, and incarceration. We recognize that the structures of social inequality impact the lives and options of affected communities differently, and work to uphold every individual’s right to health and well-being, as well as in their competence to protect themselves, their loved ones, and their communities.

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