



# STEPS

living positive, being healthy



Finding out that you are HIV positive may be an overwhelming experience that could cause you to feel afraid, confused and angry. Having these feelings and moving through acceptance is a normal part of understanding your diagnosis. Over time, many newly diagnosed people learn ways to help them cope with their diagnosis and move forward to lead healthy and happy lives.

If you just learned you are living with HIV, it is important to empower yourself by understanding as much as you can about the virus, your diagnosis and to seek lifestyle changes that can help you improve your long-term health and well-being.

This booklet is a resource guide meant to encourage you to take control of how you feel and live. Inside you'll find a number of resources that can guide you to organizations and agencies that can assist you with medical appointments, support groups, and many other services that you may need. In the back, a list of websites provides more information about HIV locally, nationally and worldwide, and you will find worksheets to help keep you on track.

You will find that you are not alone. Many people live long and fulfilling lives with HIV. Many communities and organizations are working together to support and help people just like you. Questions like, "What kind of doctor should I see?" or "Does having HIV mean that I'm going to die?" will be addressed inside this booklet.

**Acceptance and peace will come, but only with time.**

**Your life is not over, though it may feel that way right now.**

**Its value has not diminished; its meaning has not been lost.**

You are the same person that you were before you got your diagnosis. Yes, this may be the most shocking thing to ever happen to you, but you are resilient and adaptive! Your life may change, but everybody's life goes through changes in their journey. This is simply a turning point. Once you make it through the immediate shock, you will do what many have done before: learn, adjust, grow and move forward.

This is life-changing news, but you have life-enhancing options. This booklet has recommended steps that are designed to help you start your journey toward a path that supports you and your physical, mental and emotional health. Staying healthy has never been more important, and you can do it - just take it day by day and step by step.

It's OK if you struggle with mental and emotional health and it's OK to ask for help. The Ohio CareLine is a toll-free, confidential support service created by the Ohio Department of Mental Health and Addiction Services. The CareLine is available 24/7 and is staffed with licensed behavioral health professionals. **1-800-720-9616 or text "4hope" to 741741**

## STEP 1: STOP & BREATHE

You may not have had a moment's mental peace since being diagnosed. Take it now. Close your eyes and take a deep breath in through your nose and out through your mouth.

Focus on your breathing for a moment, allow your mind to be clear. Remember how good this feels. It may be your best defense over the coming days, months, and years as you process this moment.

## STEP 2: FOCUS ON THE PRESENT

Right now, your imagination is your worst enemy. Your mind is probably thinking about your future and the bad things that could occur.

Be focused on the present, because that's the time you have; it's the only time you've ever had.

Nobody can change the past or control the future, but you can address the present. What you do right now can help shape your future.

## STEP 3: FORGIVE YOURSELF & OTHERS

Stop blaming yourself for what happened. Stop blaming who might have given you HIV.

Blame usually leads to anger, and anger can lead to violence and hate, towards yourself and others.

Forgiving yourself allows you to start healing, and to forgive others in time.

## STEP 4: LET GO OF ANGER & REVENGE

Feelings of anger and revenge toward who might have given you HIV may lead to violence and hatred.

Acknowledge your feelings, then let them go.

Do not act on these feelings, but do discuss them with others who have experienced this before.

Talk to a counselor, social worker, or case manager.

Learn to forgive them!

## STEP 5: MAKE YOUR OWN EXPERIENCE

Everyone's life experience is a unique set of events and outcomes. Don't get caught up in what has happened to other people with HIV.

Your experience is what you make of it.

What happens in your future is unique to you; it is shaped by what you do in the present.



## STEP 6: USE YOUR SUPPORT NETWORKS

Support networks are people in your life who are on your side when you need them, helping you without judgment, lectures, or hesitation.

Support networks take on different forms for each person. Yours may be family members, close friends, or a mixture of both.

See page 31 for more information to help you identify your support networks.

## STEP 7: GET INTO CARE

Many people with HIV see an Infectious Disease or Special Immunology doctor. These “Specialists” may be more likely to know about the latest treatments for HIV.

You have a choice of which doctor you see for your medical care. Make your decision based on their knowledge of HIV and your comfort level with them.

Don't let pride or embarrassment stop you from telling your doctor the truth. Your long-term health is at stake. Getting into care can improve your health and reduce or eliminate your chances of passing HIV to others.

**Undetectable = Untransmittable**  
(U=U)

Prepare a list of questions for your doctor and take them with you to your first appointment.

See page 18 for information on why getting into care is important, page 58 for helpful resources on preparing for your first appointment, and page 50 for a guide on health insurance and disability benefits.

## STEP 8: MANAGE INFORMATION OVERLOAD

People commonly have two extreme reactions after being diagnosed. They either completely avoid any mention of HIV, or they seek out, read, and absorb as much information as they can about the subject.

Aim for information flow control. That means figuring out how much information about HIV is enough for you at a particular time.

It is up to you to set your own limits on what you can handle.

# BASIC HIV INFORMATION

## What is HIV?

- ▶ HIV (Human Immunodeficiency Virus) is a **virus** that can make you sick.
- ▶ Viruses are tiny particles that can harm your body by entering your cells, or even destroying them.
- ▶ The flu, chicken pox, and hepatitis are common viruses. Some (like HIV) can weaken your immune system.

## What is the Immune System?

- ▶ Your immune system protects your body from illness.
- ▶ It is made up of many kinds of cells that work to protect your body and fight off things like bacteria, viruses, parasites, or other things that could make you sick.

You can get more information here: [www.cdc.gov/hiv/basics](http://www.cdc.gov/hiv/basics)

## What are CD4 Cells?

- ▶ **CD4 Cells** (AKA helper T cells or T cells) are an important part of your immune system. They help fight off infections and keep you from getting sick.
- ▶ HIV attacks and destroys your CD4 cells. Taking HIV medications can help protect your CD4 cells from HIV.
- ▶ Your **CD4 Count** is the total number of CD4 cells you have in your body; the more you have the healthier you'll be.
- ▶ A healthy adult has between 500-1600 CD4 cells per cubic millimeter of blood.

## What is a Viral Load?

- ▶ Your **viral load** is a measure of how much HIV is in your blood. It can range from undetectable (very low) to millions (very high), depending on how active the virus is within you.
- ▶ Your doctor will do blood work to keep track of your CD4 count and viral load. This is to look at how healthy you are and see if your medications are working. Ideally, blood work will show a high CD4 count and a low viral load.

## What is AIDS?

- ▶ **AIDS** (Acquired Immune Deficiency Syndrome) is the most severe phase of HIV infection.
- ▶ You can develop AIDS if your immune system is so badly damaged by HIV that it can't protect your body from infections.
- ▶ You will receive an AIDS diagnosis if HIV destroys too many CD4 cells (your CD4 count drops below 200) or if you develop an opportunistic infection (an infection that your body would normally be able to fight off if you were healthy).
- ▶ Common symptoms of AIDS include chills, fever, sweats, swollen lymph glands, weakness, and weight loss. People with AIDS can have a high viral load and pass HIV to others more easily.
- ▶ Taking HIV medications can prevent you from developing AIDS because it keeps your **CD4 count up** and your **viral load down**.

## HOW IS HIV TRANSMITTED?

A person gets HIV from someone who has the virus. You can't tell if someone has HIV by looking at them; the only way to know for sure is a blood test. Blood, breast milk, vaginal fluids, semen, pre-cum, and rectal fluids can carry HIV.



Condomless anal, oral,  
or vaginal sex with a  
person living with HIV



Sharing needles  
with someone living  
with HIV

In 2021, the most common way people in Ohio got HIV was by having sex or sharing needles with someone who has it.

For more information on safer sex and drug use, see pages 41-44.



Pregnant people living with HIV can pass the virus to their child



Chest feeding people living with HIV can pass the virus to their child



Blood transfusions



Transplanted organs from infected donors

HIV could also be transmitted by pregnancy or chest feeding. With medical care and treatment, people living with HIV can give birth and breastfeed HIV-negative infants.

See page 39 for more information on family planning and HIV.

HIV transmission by blood transfusion or organ transplantation is very rare. People living with HIV are not allowed to sell or donate blood in the State of Ohio.



# YOU CANNOT TRANSMIT HIV BY:



Kissing, Touching,  
Hugging, or Shaking  
Hands



Preparing food for  
others, or sharing  
dishes and utensils



Working or going to  
school with others



Coughing or  
sneezing



Using a public  
or private  
bathroom



Going to a  
public pool



Sharing a  
toothbrush



Insect bites

# UNDETECTABLE = UNTRANSMITTABLE

## What this means:

- ▶ If you take your medication (as directed by your doctor) every day, you can reach an undetectable viral load, and **have no risk of transmitting HIV through sex.**

$$U=U$$

- ▶ You may still be able to transmit HIV through injection drug use. HIV treatment can reduce your risk, but safer injection practices are still important to prevent HIV transmission.
- ▶ You may still be able to transmit HIV when you are pregnant or chest feeding. Prenatal care and an undetectable viral load can dramatically reduce the chance of transmitting HIV to babies.

# ANTI-RETROVIRAL THERAPY & WHY IT MATTERS

- ▶ **Anti-retroviral therapy (ART)** is a combination of HIV medications.
- ▶ Doctors recommend starting ART right away. It will protect your CD4 cells and keep your immune system strong. Treatment will help you reach an undetectable viral load and stay healthy.
- ▶ Start by having an honest conversation with your doctor. Ask them about all your options, including diet and lifestyle changes.
- ▶ Ask about side effects, and tell your doctor, nurse, case manager, and pharmacist about any other medications, supplements, or vitamins that you are taking. ART will not interfere with hormone replacement therapy.
- ▶ It helps to get all of your medications from the same place so that the pharmacist can keep track of your medications and their side effects or interactions.

## WHAT IS ADHERENCE?

- ▶ **Adherence** means sticking to something. It's very important to take your HIV medications when and how you are supposed to take them.
- ▶ When you miss doses of your treatment, your viral load can go up and the virus could change. This means your medicine could stop working as well. Each time this happens, you could have fewer choices for medicines.
- ▶ Your meds will control your HIV best if you miss no more than one pill per month.
- ▶ Once you and your doctor decide on a medication, it is important to take it exactly as they tell you (with or without food, with a glass of water, at a certain time of day, etc.).

## TOOLS TO HELP WITH ADHERENCE

- ▶ People living with HIV can struggle with medication adherence for a variety of reasons. For example, some people avoid taking their HIV meds because it reminds them of the social and emotional issues connected to HIV. Other people might struggle with side effects, or be overwhelmed by responsibilities like childcare.
- ▶ There are tools (like pillboxes, phone alarms, and automatic refills at the pharmacy) that can help you remember to take your meds. If you have a smartphone, search your app store for “pill reminder” to find an app that can help you remember.
- ▶ Talk to your doctor or pharmacist if you're having trouble, especially if you're experiencing side effects. They can help you make a plan to help you feel better.

# SYMPTOMS MANAGEMENT

Symptoms of HIV or possible side effects of ART:

- Diarrhea
- Dry/sore mouth
- Fatigue
- Headaches
- Nausea
- Pain and nerve problems
- Dry skin
- Rash
- Appetite changes and weight loss

Some symptoms may be temporary as your body adjusts to the medication.

Your doctor can prescribe medications for your side effects. Make sure to talk with your doctor before trying any home remedies - some may not mix well with your medication.

Page 62 has a chart to help you keep track of your symptoms.

# WHEN TO CALL YOUR DOCTOR

People may experience many possible side effects from their medication. Discuss any symptoms with your doctor and pharmacist.

---

## Call your doctor right away (or 911) if you have:

- Rapid swelling in one area or over the entire body. Especially if it involves the lips, tongue, mouth, or throat.
- Difficulty breathing or swallowing
- Low blood pressure, shock, or unconsciousness
- A rash or hives

## Call your doctor within 24 hours if you have:

- Fever
- Confusion or lightheadedness
- Abdominal pain
- Severe weakness
- Severe headache
- Nausea or vomiting
- Jaundice (yellowing of the eyes and skin)
- Diarrhea including dark urine, lightheadedness, muscle cramps
- Blood in your stool

## Talk to your doctor within a few days if you have:

- Muscle pain
- Mild weakness
- Mild headache
- Loss of appetite
- Changes in body fat
- Nervousness or anxiety
- Burning or tingling in the feet
- Strange dreams or difficulty sleeping
- Any other symptoms that are bothering you

# DISCLOSURE

**Disclosure** means telling someone that you are HIV-positive. Who to tell about your HIV status and how to tell them is a complicated and personal decision.

## Who should I tell?

- ▶ Tell people with whom you have had sexual contact.
- ▶ Tell people with whom you have shared needles.
- ▶ Tell your doctors and other healthcare providers so you receive appropriate care.

[Doctors may ask how you were exposed to HIV to determine if you are at risk for things like Hepatitis C (HCV) or other Sexually Transmitted Infections (STIs)]

- ▶ For many people, telling those closest to them provides emotional and needed support.
  - ▶ Remember: You can always tell someone about your status later, but you can never “untell” someone.



## WHO CAN HELP: DISEASE INTERVENTION SPECIALISTS

- ▶ Ohio has highly skilled public health workers, from your local health department, called Disease Intervention Specialists (DIS).
- ▶ DIS will contact you and ask for a list of past sex or injection drug partners so they can let them know they may have been exposed to HIV.
- ▶ **DIS will not disclose your name**, but they will contact your partners, and can provide free HIV testing, or connect them with a clinic for free testing.
- ▶ They may also link you to medical care or work with a Linkage expert that can help.
- ▶ These conversations may be uncomfortable, but it is very important that you be honest with DIS to protect yourself and others.

## WHO DO I HAVE TO TELL?

### “Disclose Before Exposure” - It’s Ohio Law

It is a second-degree felony to have sexual contact (anal, vaginal, or oral) with someone without telling them that you are HIV-positive.

Ohio law [ORC 2903.11(B)] requires that you disclose your status before *exposing* or *transmitting* HIV to someone else. In most cases, sharing your HIV status is a personal choice, but when it comes to sex, it is a legal requirement.

Even if you do not transmit HIV to your partner or you are undetectable, you could still be prosecuted.

Contact OHIV, Ohio’s HIV hotline, if you have questions about Ohio law and HIV.

<https://ohiv.org/>

1-800-332-2437

## WHO DO I WANT TO TELL?

It helps to plan ahead. There is no one best way to tell someone, just as there is no sure way to know how they will react. It will help to ask yourself a few questions first:

- ▶ Who do I want to tell and why do I want them to know?
- ▶ How much am I ready to share? How much are they ready to hear?
- ▶ How will disclosing my HIV status affect me? How will it affect my relationships with the people around me?

Consider where you want to disclose. It could be at home, at a friend's house, or in a healthcare setting.

It may never feel like the right time - you should tell people when you feel ready or when you are legally required to do so.

---

## People I've told about my status

Name	Reason for Disclosure	Results

---

## People I would like to tell about my status

Name	Pros	Cons

---

## HOW WILL SHARING MY STATUS AFFECT ME AND OTHERS?

- ▶ Disclosing your HIV status can be stressful. As you deal with your diagnosis, sharing your status may also have an effect on the people you tell. While you may receive love and support from some, others may react negatively or need time to process on their own.
- ▶ You may encounter questions, fears, or preconceived notions about HIV.
- ▶ Just like you, people you tell may need support too. You can share websites and pamphlets with them, or give them phone numbers to ask questions. You can also let them know who else is aware of your status so that they know who they can talk to for support, or to support you.

# SAFETY AND VIOLENCE

Think about how your current or previous partners may react before you tell them about your HIV status. Could they be angry? Is it safe for you to tell them?

If you're concerned that it would be unsafe for you to tell a sexual or needle-sharing partner that they may have been exposed to HIV, remember that Ohio DIS can help your partners get tested for HIV without telling them that you have HIV.

Abuse can be verbal, emotional, financial, sexual, or physical - and can happen to anyone, regardless of gender, age, orientation, or ability. There are resources that can help if you're concerned about relationship safety or violence:

- ▶ The National Domestic Violence Hotline: 1-800-799-SAFE (7233) or text "START" to 88788. [www.TheHotline.org](http://www.TheHotline.org).
- ▶ BRAVO (Buckeye Region Anti-Violence Organization): 1-866-86BRAVO (27286) or text 614-333-1907. [www.bravo-ohio.org](http://www.bravo-ohio.org).

# WHAT DOES SUPPORT LOOK LIKE?

Your support network gives you emotional and practical help when you're having a difficult time. This can be *formal* or *informal*.

## Formal Support

Individuals from agencies that provide you with services

Doctors, case workers, & counselors

## Informal Support

People from your social network

Friends, family, co-workers, neighbors, and your faith community

You may find that telling those in your **informal** network makes you feel more supported.

There is a worksheet on page 57 that can help you visualize your support network. You can find formal supports starting on page 47.

## DISCLOSING TO CHILDREN

If children are a part of your life, it is important to ask yourself why you want to tell them:

- ▶ Will they be angry if you keep a secret?
- ▶ Do they suspect something?
- ▶ Do you look or feel sick?

Children can react to the news of HIV in many different ways. Older kids may be upset that you kept a secret from them. Younger children may not show emotion because they are just too young to understand. You may decide only to tell them as much as you consider appropriate for their age.

**Do not forget that kids need support too.** Give them the name of another trusted adult they can talk to. There are books and online resources that can guide families with HIV. [“Show and Tell: How to Disclose Your HIV Status to Your Kids,”](#) is a great article on that can help you plan.



## WHO DOES NOT NEED TO KNOW?

You do not have to tell family, friends, or the general public that you are HIV-positive. You do not have to tell your employer that you have HIV. If you do tell, remember that as long as you are performing your job, your employer cannot legally discriminate against you.

People with disabilities, including HIV, are protected from job discrimination by the Americans with Disabilities Act (ADA). <https://www.ada.gov/hiv/> has more information.

If you are planning to disclose at work for employee or benefits purposes (like reasonable accommodation, insurance, disability, or medical leave), contact an employee benefits counselor or an HIV legal advocate before disclosing.

# STAYING HEALTHY

## The Importance of Healthy Choices

- ▶ You can stay healthy or even improve your health by keeping your immune system strong.
- ▶ A strong immune system helps fight infections. It can give you more energy and repair damaged tissues. To make your immune system strong, you may need to make changes in your lifestyle.
- ▶ Making changes can be hard, but the benefits can make your life feel more relaxed and less stressful.

## EATING WELL

- ▶ A good diet gives you the energy and nutrition you need to maintain weight and prevent other health problems.
- ▶ Eat food from each food group every day. Make fruits and vegetables half of your plate. Make half of your grains whole grains.
- ▶ Remember to drink plenty of water, at least 9 eight-ounce glasses a day.
- ▶ Start with small changes - each change is a personal win for your health!
- ▶ Some people with HIV feel better while eating a diet that includes lots of protein and anti-inflammatory foods (like nuts, olive oil, and fish).
- ▶ Some people with HIV may need to eat more calories to avoid losing weight.
- ▶ Talk to your doctor, or ask a dietitian to help you find a diet that works for you.



## APPETITE LOSS & DIFFICULTY EATING

Eating and getting proper nutrition for your body is very important to stay healthy and support your immune system. People with HIV often have trouble eating for a variety of reasons. You should see a dietician or your doctor if you're having trouble.

- ▶ Eat small, frequent meals instead of a few large ones.
- ▶ Try liquid nutritional products.
- ▶ Fill up on nutritious, higher-calorie items.
- ▶ Try drinking liquid 30 minutes before eating, instead of with your meal.
- ▶ Keep easy-to-prepare foods on hand, and make your favorite foods.
- ▶ Remember to keep drinking fluids even if you don't have an appetite.

## NAUSEA & DIARRHEA

- ▶ When you're feeling better, eat larger meals.
- ▶ When you're feeling nauseated, avoid your favorite foods to prevent bad associations.
- ▶ Avoid very sweet or greasy foods.
  - ▶ Try the BRAT diet (Bananas, Rice, Applesauce, and Toast) if you're feeling very ill.
- ▶ Eat saltier foods to help you stay hydrated.
- ▶ If you're losing fluids and electrolytes through vomiting or diarrhea, make sure you're drinking lots of water or electrolyte-replenishing products (like sports drinks or oral electrolyte drinks), and eating high-potassium foods (like bananas, kale, or potatoes).
- ▶ Experiment with what kinds of foods make you feel sick. For example, lactose (in dairy products) can cause diarrhea in some people, and certain vegetables or beans **37** can give people gas or cramps.

## STAYING FIT

- ▶ If you don't regularly exercise, now is the time to start. Start slow and simple, like a 20-minute walk 3 days a week. Slowly build up the duration and frequency of your workouts. A good goal is 45-60 minutes of exercise 4 or 5 days a week.
- ▶ Some people find it easier to break up exercise into three 14-20 minute workouts each day. An example is a 20 minute bike ride in the morning, a 20 minute walk after lunch, and walking the dog for 20 minutes in the evening. Do whatever works for you!
- ▶ Do a combination of exercises for strength (like lifting weights), flexibility (like yoga), and endurance (like jogging).
- ▶ Talk with your health care provider before starting any exercise plan.

## STAYING RESTED & CALM

- ▶ Get plenty of sleep, 7-9 hours a day.
- ▶ Find some time to just relax your body. Meditation may be a good strategy.

## FAMILY PLANNING & HIV

- ▶ Everyone has the right to decide the number and spacing of their children, if they want to have children at all. Talk to your doctor about methods of family planning and contraceptive options.
- ▶ While most hormonal contraceptives are unaffected by ART (HIV medication), there could be some interaction. Talk to your doctor or pharmacist about any possible interactions or side effects.
- ▶ Pre-Exposure Prophylaxis (PrEP) is a medication that HIV-negative people can take to reduce the risk of them getting HIV. You may want to talk to your HIV negative partner(s) about taking PrEP.
- ▶ If you are pregnant or thinking about getting pregnant, learn all you can about pregnancy and HIV from your doctor or HIV service agencies. People living with HIV are at higher risk for complications during pregnancy. High-risk pregnancy specialists can help you stay healthy and deliver healthy children without transmitting HIV.
- ▶ Adoption is also an option if you want children - the Americans with Disabilities Act prohibits discrimination against individuals or couples with HIV.

## WHAT IS HARM REDUCTION?

Harm reduction is any behavior or strategy that helps reduce harm to yourself or others. For example, to reduce the risk of transmitting HIV to others, you can practice safer sex or safer drug use.

- ▶ Harm reduction strategies are aimed at improving individual and community quality of life, instead of focusing on eliminating all drug use or behaviors that put people at risk.
- ▶ Harm reduction is focused on social justice, built on respect for the rights of people who use drugs. It also recognizes that poverty socioeconomic status, racism, social isolation, past trauma, and sex-based or gender discrimination affect your chances of experiencing harm.
- ▶ Harm reduction does not attempt to minimize or ignore the harm or danger associated with drug use. For more information on drug use and HIV, see page 43.
- ▶ The Harm Reduction Coalition ([www.harmreduction.org](http://www.harmreduction.org)) has a lot of good information about harm reduction services.



## PRACTICING SAFER SEX

- ▶ The most effective method of prevention is to take your HIV medication and get an undetectable viral load. This means that you cannot transmit HIV to your sexual partners. Remember that **Undetectable = Untransmittable**
- ▶ Practicing safer sex can help protect others from HIV, and protect you from sexually-transmitted infections (STIs) and other infections.
- ▶ Receptive (“female”) and insertive condoms (“traditional”) can be effective barrier methods in preventing transmission of HIV or STIs. The Ohio HIV Hotline ([OHIV.org](http://OHIV.org)) offers free condom delivery, and many local health departments also give away free condoms.

## PRACTICING SAFER SEX

- ▶ If you have a regular sexual partner(s), they can also take Pre-Exposure Prophylaxis (PrEP) - a once-daily pill that reduces risk of HIV by over 90%. Ohio's PrEP assistance program, PAPI, can help pay for PrEP care if you or your partner(s) can't afford it. To talk to someone about enrolling in PAPI or taking PrEP, call the Ohio HIV hotline or visit their website: [OHIV.ORG](http://OHIV.ORG), or 1-800-332-2437.
- ▶ Post-Exposure Prophylaxis (PEP) is a short-term medication that people can take after being exposed to HIV to prevent them from becoming HIV positive. This medication must be started within 72 hours of exposure to be effective at preventing HIV infection.

## PRACTICING SAFER DRUG USE

Alcohol and other drugs can weaken your immune system and harm your liver. HIV meds can interact with other drugs in a way that could worsen your side effects. Talk to your doctor or pharmacist about all drugs you are taking to minimize harmful side effects.

- ▶ **Alcohol** specifically can damage your liver, which plays an important role in processing your HIV medication. Drinking alcohol can be more harmful for people living with HIV than for HIV-negative people.
- ▶ Smoking **tobacco** can be a serious health problem for everyone, but is especially dangerous for people living with HIV. You are more likely to develop harmful consequences of smoking than those without HIV. Quitting smoking can help you have a better quality of life, fewer HIV-related symptoms, and a lower risk for serious illnesses including heart attacks and pneumonia.

## PRACTICING SAFER DRUG USE

- ▶ In some studies, **caffeine** has actually been linked to *better* outcomes from people living with HIV and hepatitis. Consuming a healthy level of caffeine (found in coffee, tea, chocolate) may help you feel better.
- ▶ If you **inject drugs**, do not re-use or share needles or other equipment. Many HIV infections occur when people share needles to inject drugs. It is best to use fresh needles each time; this eliminates any risk of getting new infections (like hepatitis) from others, or transmitting HIV to your partners. Find out if your city offers a needle exchange program, or a safe place to dispose of needles.

**A potential harm reduction strategy for HIV is to decrease or stop drug and alcohol use.** If you are not able to stop drug use, cutting back could still help your health. Consider seeking out what works for you: drug treatment programs, Medication-Assisted Treatment (MAT) therapy, or addiction recovery support groups are all options.

# CO-INFECTIONS AND HIV

People with HIV may be at a greater risk of getting other infections.

Some common coinfections are:

- ▶ Tuberculosis (TB)
- ▶ Hepatitis A Virus (HAV)
- ▶ Hepatitis B Virus (HBV)
- ▶ Hepatitis C Virus (HCV)
- ▶ Some cancers

Getting regular treatment from your doctor can help you stay healthy. Your doctor can test you for co-infections, and can vaccinate you to prevent HAV and HBV. Practicing safer sex and drug use can also help protect your health and prevent you from getting co-infections.

## STIS AND HIV

Besides coinfections, you may be at higher risk for getting sexually-transmitted infections (STIs). Some STIs (like syphilis and herpes) can have open sores, which make it more likely that you will transmit HIV to a partner.

Some common STIs in Ohio are:

- ▶ Syphilis
- ▶ Chlamydia
- ▶ Gonorrhea
- ▶ HPV (anogenital warts)
- ▶ Herpes

You can protect yourself and your partner(s) by practicing safer sex, and getting regular STI tests. You can also protect yourself from HPV by getting vaccinated. Talk to your doctor about your options.

# HIV SUPPORT SERVICES

It is important that you get the medical and social support services that you need to maintain a healthy lifestyle. Take charge of your health care by honestly telling medical and service professionals what you need.

## Tips for Getting Services

- ▶ Always get a contact person's name and phone number.
- ▶ Ask questions if you don't understand
- ▶ Keep a copy of everything
- ▶ Write down questions for medical and service providers before appointments

## Know Your Rights

- ▶ The Americans with Disabilities Act protects people living with HIV from discrimination ([www.ada.gov/hiv](http://www.ada.gov/hiv)).
- ▶ In Ohio, no one can share your HIV/AIDS status with anyone else without your written permission.
- ▶ Ask your local HIV service organizations about these and other laws.

## SERVICE PROGRAMS YOU MAY HEAR ABOUT

Two of the most important programs are ADAP and Ryan White. Page 49 has listed more programs that you may find helpful.

**AIDS Drug Assistance Program (ADAP)** - pays all or part of the cost of HIV drugs and other prescribed medication for those who qualify.

**The Ryan White Program** - The Ryan White Program is a federally-funded program designed to assist people living with HIV with a variety of HIV care services. Eligibility for services is determined based on several factors including income, geographic location, age, and sex. Case Managers serve clients in all 88 counties and can help you access and pay for many services in your area including medical, dental, and mental health care.

**For more information, call the Ohio HIV Hotline at  
1-800-332-2437.**



**Cash Assistance** - state and local program offered through the Department of Jobs and Family Services.

**Health Insurance Premium Payment Program (HIPP)** - Through ADAP - helps people pay their health insurance premium.

**Medicaid** - a federal program that covers people with low-income who can't afford medical care.

**Medicare** -available for people who are receiving SSDI benefits or are over 65 years old.

**MyCare Ohio** - a managed care program for people who use both Medicaid and Medicare.

**SNAP Benefits (Food Stamps)** - helps low-income people buy food.

**Social Security Disability Income (SSDI)** - for people who pay Social Security taxes, become disabled, and have enough earned credits.

**Supplemental Security Income (SSI)** - for people who have low income and assets and are disabled, or for low-income people 65 and older without disabilities. It includes Medicaid coverage and is available through the Social Security office.

**Temporary Assistance for Needy Families** - for low-income families with children, and single, unemployed, homeless, or ill parents.

## HEALTH INSURANCE & DISABILITY BENEFITS

- ▶ If you were insured before you were diagnosed, it generally can't be cancelled or changed. The Affordable Care Act (ACA) offers protections for people living with HIV. <https://www.healthcare.gov/>
- ▶ If you weren't insured when you were diagnosed, your local Ryan White case manager can help you get insurance or enroll in Ryan White coverage.
- ▶ You may also be eligible for Medicaid or Medicare: MyCare Ohio can help if you're eligible for both.
- ▶ Coverage to Care is a resource from the US Gov Centers for Medicaid & Medicare Resources that can help you get into care. <https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/c2c>.
- ▶ Many people living with HIV continue to work as they did before their diagnosis. If your job offers sick, personal, or vacation time through your job, consider using it if you need a break from work. If that isn't an option for you or you are unemployed, you may think about applying for unemployment or disability benefits at <https://www.ssa.gov/>.

# IMPORTANT HIV WEBSITES

## General Information

Brochure on HIV and Treatment: <https://hivinfo.nih.gov/>

U.S. Health & Human Services: <https://www.hiv.gov/>

HIV/AIDS Bureau Website: [www.ryanwhite.hrsa.gov/](http://www.ryanwhite.hrsa.gov/)

Positively Aware: [www.positivelyaware.com](http://www.positivelyaware.com)

AIDS Map: [www.aidsmap.com](http://www.aidsmap.com)

HIV Magazines/Blogs: [www.thebody.com](http://www.thebody.com) ; [www.poz.com](http://www.poz.com)

## Ohio-Specific Information

Ohio HIV/AIDS Hotline: <http://ohiv.org/> | 1-800-332-2437 | Live chat on website

Ohio Department of Health:  
<https://odh.ohio.gov/wps/portal/gov/odh/home>

Ohio Ryan White Part B: <https://odh.ohio.gov/know-our-programs/Ryan-White-Part-B-HIV-Client-Services/welcome-to>

## Clinical Trials

National Database for Clinical Trials: <https://aidsinfo.nih.gov/clinical-trials>

Ohio State Clinical Trials: <https://wexnermedical.osu.edu/infectious-diseases/infectious-diseases-clinical-trials-unit>

Cincinnati Clinical Trials: [http://idc.uc.edu/about\\_us.php](http://idc.uc.edu/about_us.php)

Case Western Clinical Trials: <http://medicine.case.edu/divisions/infectious-diseases-and-hiv-medicine/research/>

## HIV Testing and Care

CDC's National HIV Testing Resources Index: <https://gettested.cdc.gov/>

GHMA Treatment Issues: [www.gmhc.org](http://www.gmhc.org)

AIDS Treatment Network: <https://actgnetwork.org>

HIV and Women: [www.thewellproject.org](http://www.thewellproject.org)

Pediatric AIDS Foundation: [www.pedaids.org](http://www.pedaids.org)

## HIV EMPOWERMENT

San Francisco AIDS Foundation: [www.sfaf.org](http://www.sfaf.org)

Project Inform: <https://www.thebodypro.com/author/project-inform>

National Minority AIDS Council: <http://www.nmac.org/>

United Nations Programme on HIV/AIDS: [www.unaids.org](http://www.unaids.org) Improving

Women's Health: [www.engenderhealth.org](http://www.engenderhealth.org)

AIDS Education and Training Center: <https://aidsetc.org/>

## GLOSSARY: DEFINITIONS & ACRONYMS

**ACA: Affordable Care Act** - Also known as Obamacare; legislation that protects people living with HIV from health insurance discrimination.

**AIDS: Acquired Immunodeficiency Syndrome** - Disease caused by HIV (human immunodeficiency virus).

**ASO: AIDS Service Organization** - An organization that provides medical or social support services primarily or exclusively to people with and affected by HIV/AIDS.

**CBO: Community Based Organization** - An organization which provides services to locally defined populations, which may or may not include populations infected with or affected by HIV/AIDS.

**CD4 Count:** The most commonly used surrogate marker for assessing the state of the immune system. The higher your CD4, the better.

**CDC: Centers for Disease Control and Prevention** - The Federal agency within the U.S. Department of Health and Human Services that administers HIV/AIDS prevention programs, including the HIV Prevention Community Planning process, among other programs. The CDC is responsible for monitoring and reporting infectious diseases, administering AIDS surveillance grants, and publishing epidemiological reports such as the HIV/AIDS Surveillance Report.

**CCPG: Community Planning Group** - A statewide comprehensive planning group for HIV care and services in Ohio.

**DIS: Disease Intervention Specialist** - A public health worker who conducts partner services for people diagnosed with HIV or other sexually transmitted infections.

**EHE: Ending the Epidemic** - A federal effort to reduce new HIV infections in the United States.

**Hepatitis** - a type of liver infection that has five types. Hepatitis A (HAV), Hepatitis B (HBV), and Hepatitis C (HCV) are all common in Ohio. HAV and HBV can be prevented by a vaccine.

**HIV Disease** - The entire spectrum of the natural history of the Human Immunodeficiency Virus, from post infection through the clinical diagnosis of AIDS.

**HOPWA: Housing Opportunities for People with AIDS** - A program administered by the U.S. Department of Housing and Urban Development, which provides funding to supporting housing for people with HIV and their families.

**HRSA: Health Resources and Services Administration** - The agency of the U.S. Department of Health and Human Services that is responsible for administering the CARE Act.

**ID: Infectious Disease** - A type of doctor that specializes in infectious diseases like HIV.

**LTC: Linkage to Care** - The process of getting people diagnosed with HIV into medical treatment, and helping them navigate health and social service systems.

**OI: Opportunistic Infection** - An infection a person with HIV gets because of their weakened immune system. OIs are diseases or infections rarely seen in people with normal immune systems.

**PEP: Post-Exposure Prophylaxis** - Short-term treatment started as soon as possible (within 72 hours) to reduce the risk of HIV infection after exposure. Can be for occupational or non-occupational exposure

**PLWH/A** - People Living with HIV/AIDS

**PrEP: Pre-exposure Prophylaxis** - A once-daily pill taken by HIV-negative people at high risk of HIV to prevent infection.

**PWID** - People Who Inject Drugs

**RAGs: Regional Advisory Groups** - Regional community advisory boards who work on comprehensive HIV care planning.

**Ryan White CARE Act** - Ryan White Comprehensive AIDS Resources Emergency Act. The federal legislation created to address the health care and service needs of people living with HIV disease and their families in the United States; enacted in 1990 and reauthorized in 2013.

**Ryan White Part A:** The Part of the CARE Act that supports HIV care in highly-impacted areas.

**Ryan White Part B:** The Part of the CARE Act that enables States and territories to improve the quality, availability, and organization of health care and support services to people living with HIV and their families.

**Ryan White Part C:** The part of the CARE Act that supports primary medical care and early intervention services to people living with HIV disease through grants to service organizations.

**STD/STI** - Sexually Transmitted Diseases/Infections.

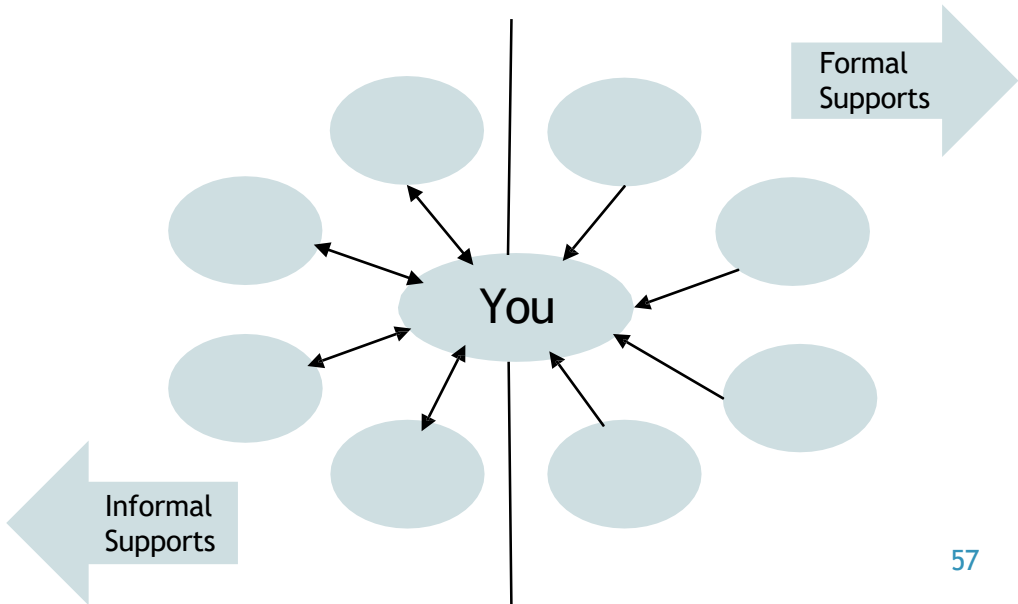
**TB** - Tuberculosis.

**U=U** - Undetectable=Untransmittable; The fact that PLWH with undetectable viral loads have no risk of sexually transmitting HIV to their partner(s).

**Viral Load** - The amount of HIV-infected cells in a cubic milliliter of blood.



# SUPPORT SYSTEM MAPPING SEE PAGE 31



# PREPARING FOR YOUR FIRST DOCTOR'S APPOINTMENT

SEE PAGE 10

## Before your Visit

Doctor/Provider:

Phone Number:

Date:

Time:

Location:

How Will I Get There?    Drive Myself    Family Member/Friend    Taxi/Ride Service  
 Bus    Other

### I struggle with:

- depression/anxiety/mental health
- relationships/dating
- religion
- family acceptance
- Other: \_\_\_\_\_

- housing
- bullying/harassment
- smoking/drugs/alcohol
- sexuality/gender
- sex/STIs/pregnancy

**Today I have/would like to talk about:**

**Today I have questions about:**

Q:

A:

Q:

A:

Q:

A:

## CD4 COUNT AND VIRAL LOAD CHART

Lab Date	CD4 Count	↑ or ↓	Viral Load	↑ or ↓

# SYMPTOMS MANAGEMENT ACTION PLAN SEE PAGE 23

Side Effect	How you are affected by symptoms	Steps you are currently taking	What you can try now	When to tell your doctor/provider

## PHARMACY & INSURANCE INFORMATION

Pharmacy		Insurance
Name:	Phone:	Plan Name:
Address:		Member / Group ID:
Contact:		Effective Date:
Doctor's Office (for refills):		Address:
Allergies:		Phone:
Notes:		Notes:

## IMPORTANT NAMES & PHONE NUMBERS

	Name	Phone Number	Email Address
Test Counselor			
Linkage to Care Coordinator			
DIS Worker			
Case Manager			
Doctor/Provider			
Pharmacist			
Emergency Contact			
Emergency Contact			