

# **KNOW YOUR RIGHTS**

Step into your Power by Knowing your Rights

Let this be your guide as you take control of your Health, your Rights, and your Life.

# **GENERAL INFORMATION**

### **Know HIPAA**

HIPAA stands for Health Insurance Portability and Accountability Act. It was passed in 1996 as a federal law that sets a national standard to protect your medical records and other personal health information. This is information that identifies an individual and is maintained or exchanged electronically or in hard copy. If the information has any parts that could be used to identify a person, it would be protected. The protection stays with the information as long as the information is in the hands of a covered entity or a business associate.

### **Patient Advocacy**

Patient advocacy is a specialized area of healthcare that is centered on the support and needs of patients. A patient advocate helps guide you through the healthcare system. This includes help going through screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer. A patient advocate also helps you communicate with your healthcare providers so they can get the information they need to make decisions about your health care along with you. Patient advocates may also help set up appointments for doctor visits and medical tests and obtain financial, legal, and social support. They may also work with insurance companies, employers, case managers, lawyers, and others who may have an effect on your healthcare needs. Advocacy helps you access efficient and accurate health care with minimal stress.

#### **Document Symptoms**

At the onset of symptoms of illness, keeping a symptom diary can help you see things about your illness that you would not see otherwise. It gives you control and direct involvement in the treatment plan. It also saves you time at the doctor's office—a one-page symptom diary review takes less time than it takes to verbally interview a patient for information. It organizes the patient's history for more meaningful clinical interpretation. A diary helps the physician identify similar symptoms within a disease process and can directly lead to activity adjustments and lifestyle changes that enhance overall function. Document your symptoms so that your doctor can follow the illness and decide whether or not the treatment plan is effective or if it needs to be changed. Sometimes, talking with a healthcare provider can be intimidating and overwhelming, and by having a symptom diary it is easier to make sure you communicate what is going on with your body more fully.

## **Communication Techniques**

Doctors are busy, so it is important to make the most of the limited time you have with them. Communicating effectively is important so the doctor can understand your issues in order to implement the best treatment plan.

- Before a doctor's visit, think of any questions you may have and write them down, and be organized and focused on the issues you want to address.
- Let the doctor know how much or how little you want to participate in the decision making process and whether you want very detailed information about all treatment options or just general information.

- If your concerns are not being addressed to your satisfaction, be assertive. Let the doctor know you still have questions. If need be, ask if an additional appointment can be set up, if your current appointment can be extended, or if there are other staff members who can address your concerns.
- Be understanding by balancing assertiveness with respect.

# Don't Self-Diagnose

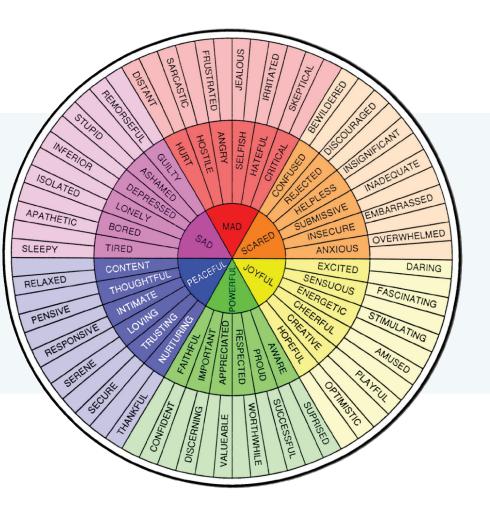
Self-diagnosis can be a dangerous path to go down. In addition, it is not likely to lead to any real answers. Some drawbacks of self-diagnosis are:

- Having an unlimited supply of information doesn't mean you have the years of training and hands-on experience that help form a diagnosis made by a professional.
- It's hard to see yourself objectively and easy to lack insight into the workings of your own mind. Providing an outside perspective is part of what professionals do. That's why even psychiatrists, for example, shouldn't self-diagnose.

# FEELING WHEEL

Dr. Gloria Willcox

Taking time to check in with yourself, allows you to see where you are emotionally so that you can move to a more peaceful place



- From a practical standpoint, being able to selfdiagnose doesn't mean you can self-treat. You can't self-prescribe medications, and a self-diagnosis won't give you access to any treatment a diagnosis from a professional would legally entitle you to.
- Self-diagnosing can cause unnecessary stress and anxiety about something that may not be true. Take a step back, focus, deep-breathe, and wait for your healthcare professional to assess your symptoms and diagnose you.

# WELLNESS TIPS

### Self-Care Defined:

The practice of taking an active role in protecting one's own well-being and happiness; in particular, during periods of stress. A good place to begin is by taking deep breaths.

### Nutrition, Rest & Journaling:

Fuel your body with a healthy, nutritious, and balanced diet, and allow it to recharge each night with enough quality sleep. Expressing yourself through the act of journaling helps control your symptoms and improve your mood by helping you prioritize problems, fears and concerns. Track any symptoms day to day, so that you can identify triggers and learn ways to better control them.

### **Sex With Barriers:**

Use condoms not only to avoid the spread of HIV, but also to protect both you and your partner against other sexually transmitted infections (STI) and other types of infections.

#### Get Tested for other STIs:

An STI makes it more likely that you can transmit both HIV and other STIs to someone else. STIs can also worsen HIV and make the disease progress more rapidly.

#### **Prevent Infections & Illnesses:**

Washing your hands frequently and limiting your contact with sick people has been shown to reduce opportunistic infections. Also stay up-to-date on all of your vaccinations to reduce your risk of preventable illnesses.

## Follow Doctor's Orders about Your Prescriptions

It's crucial to take your HIV medication exactly as prescribed by your doctor. Be sure to take prescriptions at the same time every day, and always have your medication with you so that if you are away from home, you won't have to miss a dose.

# Don't Misuse Drugs or Alcohol:

Avoid illegal drugs and take prescription drugs as directed by your doctor to help protect your immune system.

# **Consider Quitting Smoking:**

Stopping tobacco will help you live healthier and feel better, as well as prevent a number of health problems and reduce your risk of serious events like heart attack and stroke.

# Manage Physical & Emotional Health Problems:

Keeping stress, depression, and pain under control can help improve your physical and emotional health, making life with HIV easier. See a mental health professional if you feel you're experiencing depression, and be sure to mention that you're taking medication for HIV to avoid potential drug interactions between depression or other medications and HIV medicines

## Exercise Mind & Body:

Physical and mental exercise can keep your mind and body strong. Regular physical exercise, such as walking, biking, running, swimming, or another activity you enjoy, keeps you physically fit and can keep both stress and depression in check, while boosting immune system wellness. Mental exercise-doing a daily crossword puzzle or playing brain-challenging games can help maintain your cognitive health.

The keys to staying healthy with HIV are within your control. Treat your body well to strengthen it, so that it can defend against illnesses that could threaten your health.



# FACILITIES

Whether you are in a mental health/substance abuse in-patient program, or in a hospital or other facility, it is important to ask questions and make sure your medical records are documented appropriately with your information. Sometimes, writing down how you feel or any questions you have during the day, makes it easier to ensure your records are documented when your medical team visits you.

Most facilities will have a brochure or other document available to summarize patient rights and responsibilities. Ask for a copy upon admission. Time with your healthcare provider is often limited, and those who have prepared in advance their questions or concerns will have the most meaningful, efficient experience.

You have the right to appoint an agent to make decisions for you in the event you are unable to give consent to medical care/treatment, or sign releases, called a Medical Power of Attorney. A Medical Power of Attorney is a document used to appoint a trusted friend or family member to make certain medical decisions on your behalf if you are unable to. While at the facility, you can also fill out Advance Health Care Directives. The facility may have forms for you to complete.

As you are released from the facility, ask for documentation of your discharge plan and follow-up instructions. Understanding your treatment plan, making adjustments with your provider when necessary, and asking questions about your ongoing care, you increase your chances of staying well. When it comes to your health and wellness, there is no such thing as a SILLY question or TOO MANY questions. If it is helpful to have an advocate or support team, please bring them.

It is important to follow your doctor's instructions. If you have questions, even days after your release, you still have the right to follow up and get the additional information you need for continued wellness.

## Disclosure

Disclosing your status is a really hard thing to decide, especially when hospitalized or in a facility for something not directly related to your HIV status.

- You DO NOT have a legal obligation to disclose your status to a healthcare provider! This is something to think carefully about and always trust your gut instinct. Here are some questions to ask:
- Do I want to share my status from a place of obligation and guilt or because I believe it is the right thing to do in this moment?
- Will the proposed treatment interfere with my current HIV medications?
- Do I feel comfortable with my medical team?

# MENTAL HEALTH DEFINED

Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we navigate stress, relate to others, and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

Always remember: our mental health is directly connected to our overall health. Our physical and emotional health definitely impacts our mental health, just like our mental health will impact us physically and emotionally. Our minds, our bodies, and our spirits are all connected so taking care of one part of it is important for overall wellness. Please remember it is ok for us to focus or prioritize our mental health-it is not selfish or wrong because all of this impacts us. Especially with mental health providers, it is important for us to know what medications they are prescribing. With any medication, make sure to ask what the side effects are, as well as how they mix with other medications. If you have a chronic condition, ask if studies have been done of the impact of said medication on people living with specific conditions. Keep a journal to document side effects, record any differences if medication is taken with certain foods, time of day, etc.

An accountability partner is someone who holds you to and supports you in keeping a commitment. Usually a trusted friend or an accountability partner is not there to force you to do something, but to remind you and check in with about the commitment, including maintenance of the commitment. Whether it's taking medication, adhering to visits, knowing when to reach out for support, an accountability partner can be helpful on a journey to mental wellness.

A PEC (Physician's Emergency Certificate) is issued after a mental health professional has determined that a person is a danger to themselves or others and is unwilling/unable to admit themselves into a facility. When a PEC is issued, it means that you can be held without your consent in a hospital or mental health facility for up to 72 hours.

#### Therapist vs. Psychiatrist vs. Counselor

Counselors work with you to determine the best way for the sessions to achieve the preferred outcomes. Being a more short-term alternative to therapy, the term Counselor can include diverse groups such as clergy and other spiritual advisors. Counseling focuses on specific issues and is designed to help you address a particular problem such as addiction or stress management. Seeing a Counselor who is not also a licensed Therapist may be cheaper, but you may not have confidentiality by law. Make sure you do extensive research on the Counselor before sharing intimate details about your life.

Therapists use a behavioral approach to therapy. It is more long-term than counseling and focuses on a broader range of issues. The underlying principle is that your patterns of thinking and behavior affect the way that you interact with the world. The goal is to help you feel better equipped to manage stresses, understand patterns in your behavior that may interfere with reaching personal goals, having more satisfying relationships, and better regulate your thinking and emotional responses to stressful situations.

A Psychiatrist is a medical doctor who specializes in preventing, diagnosing, and treating mental illness. A Psychiatrist is trained to differentiate mental health problems from other underlying medical conditions that could be present with psychiatric symptoms. They also monitor effects of mental illness on other physical conditions (such as problems with the heart or blood pressure) and the effects of medicines on the body (such as weight, blood sugar, blood pressure, sleep, and kidney or liver functioning).

# **Choosing & Changing Therapists**

Finding the right mental health professional and approach to therapy is as important as finding the right medical doctor. Once you find a professional, start with a phone call to the professional. Ask about the professional's approach to dealing with mental health issues and how that person generally works with clients. Ask about whether or not they accept insurance and how payments are handled. If you are satisfied, describe the issues you are experiencing and see if they are experienced in such issues.

If you are comfortable with them, the next step is to schedule an appointment.

# **HIV PREVENTION**

#### www.helpstopthevirus.com/hiv-prevention

4 Steps to Prevent HIV:

- KNOW how HIV spreads,
- UNDERSTAND the chance of getting HIV from different sexual activities,
- GET tested. Ask your partners about their test results. And tell them about yours,
- TALK to a healthcare provider about all the ways to prevent HIV

# **How HIV Spreads**

HIV is found in blood, semen (cum), pre-seminal fluid (pre-cum), vaginal fluid, rectal fluid, and breast milk. HIV spreads when one of these fluids from a person who has HIV enters the blood stream of a person who does not. Some of the ways this can happen are through:

- Anal, oral, or vaginal sex
- Needles, syringes, or other injection equipment
- Pregnancy, childbirth, or breastfeeding
- The likelihood of HIV being transmitted by oral is extremely negligible. Oral sex is almost universally considered not a mode of transmission by HIV science.

# Protect Yourself & the People You Care About

Start by getting tested (HIV-testing). And take these steps:

- Sexual Activity: Try talking to your partners about HIV first. Ask whether they have been tested and what the results were. Consider PrEP, a viable means of preventing HIV.
- Injection Drug Use: Utilize a local syringe service program for clean syringes.
- Breastfeeding & Pregnancy: If you have HIV, converse with your healthcare provider before breastfeeding.

# **Know Your Status**

You can't know the status of everyone in your network. But there is one person's status you can always know. Yours. That is why regular testing is important.

# HIV TREATMENT ALSO HELPS STOP THE VIRUS

# **Treatment as Prevention**

If you do have HIV, starting and sticking to treatment can decrease your viral load so much that it can't be measured by a test, making it undetectable. Sticking to treatment and staying undetectable is a big deal—it eliminates the chance of transmitting HIV through sex. Because HIV remains dormant in the body while on treatment, it is important to maintain communication and visits with your healthcare provider. And remember, being undetectable does not prevent other sexually transmitted infections from occurring. Therefore, it is important to stick to treatment, use condoms, and practice safer sex.

## **Emergency HIV Prevention**

If you do not have HIV, you should know about postexposure prophylaxis. PEP for short. It involves taking a daily pill for 28 days after contact with HIV to prevent acquiring HIV. Treatment must begin within 72 hours. PEP is currently only available from a healthcare provider, emergency room, urgent care clinic, or HIV clinic. Followup HIV testing is required. If you think you have been exposed to HIV, you must see a healthcare provider or go to a clinic or emergency room right away.

### It's All About You

There are now more ways than ever to protect yourself and help stop the virus.

Check out the HEALTHYSEXUAL® site for tips on talking to healthcare providers about all the ways to prevent sexually transmitted infections, including HIV. The Department of Health and Human Services has even more information to help you stay up to date.

### U=U

# U=U simply means UNDETECTABLE=UNTRANSMITTABLE

U=U is a simple message used to convey the effectiveness of consistently being on antiretroviral treatment (ART) for at least 6 months and maintaining treatment. Individuals will not transmit HIV if their viral load is kept below 200 copies. Once the viral load goes under 20 copies, the virus is undetectable.

U=U empowers members of the HIV community to take charge of their health, and gives them confidence they can have healthy lives and healthy relationships. The message that you can't transmit HIV reduces the stigma from fear that people living with HIV are contagious and can pass the virus in all cases. It also reinforces why it is so important to get tested, so that if someone tests positive, they can begin to take the necessary steps to take back control of their health. Plus, there are so many resources available for people to connect to and stay in care. The science behind U=U combined data from 4 large studies. In all four studies involving mixed status couples, and condomless sex, there were 0 transmissions! To learn more about U=U, you can go online at **THRIVESS.org** or call (404) 267-1519.

You may also visit:

#### preventionaccess.org & untransmittable.org

#### **HIV Criminalization**

Although a person living with HIV which is undetectable and untransmittable poses virtually no risk of passing the virus to another person, there are still laws in place that are important to keep in mind for one's awareness. During the early years of the HIV epidemic, a number of states implemented HIV-specific criminal exposure laws. Some of these state laws criminalize behaviors that cannot transmit HIV and apply regardless of actual transmission. Criminalization of potential HIV exposure is largely a matter of state law. These laws differ as to what behaviors are criminalized or what behaviors will result in additional penalties. In 19 states, laws require persons who are aware that they have HIV to disclose their status to sexual partners and 12 states require disclosure to needle sharing partners

Several states criminalize one or more behaviors that pose a low or no risk for HIV. Here in Georgia, people living with HIV can face felony charges if they know their status, fail to disclose their status, intentionally seek to transmit HIV, and then engage in sexual behavior that poses a significant risk of transmission. It is a felony crime that is punishable up to five years in prison. People living with HIV can also still be potentially prosecuted under Georgia's general criminal laws, for example, for aggravated assault.

#### **Revealing HIV Status**

If you are living with HIV, at some point, you will likely have to decide whether to disclose your HIV status. HIV criminalization laws leave less of an option of disclosing your status to your sexual partners even if you pose no risk of transmitting. You are not required to disclose to anyone else. In Georgia, you are not required to disclose your status to your sexual partner, but you cannot engage in a sexual act with the intent to transmit HIV and fail to disclose your HIV status to the other person prior to the sexual act. In general, choosing who to tell is a personal decision, and there will be times where you find yourself trying to balance being honest with protecting your privacy. Here are a few things that may help with disclosing your status.

- Be selective. In most cases, it is your choice who you tell. It is your right. However, be mindful of the HIV criminalization laws in your state. Some of these laws require disclosing status before sexual encounters, before sharing injection drugs or equipment, or receiving medical care.
- Make sure you consider. Consider who you need to tell. What do you want to tell them about living with HIV? What you expect from the people you are disclosing your status to? When is the appropriate time to tell them? Where is the best place to have this conversation? Why are you telling them? Would they respond in a dangerous manner?
- Be loving with yourself by taking your time to consider who to tell and how to tell them.

- Be unapologetic. Living with HIV does not mean you have a reason to apologize to anyone.
- Remember to keep it simple and straightforward with the facts.
- If you are unable to tell close friends, family members, or other loved ones about your HIV status, you can get support and experience from others in the HIV community.
- There are also online discussions and groups you can join.
- Trust yourself. There is no perfect way to share your status. Find a way that is loving to you. Also remember that you are not alone. Others have had to deal with this same experience and have gotten through it. You will as well.



# For more information & additional resources, visit:

# www.frontlinelegalservices.org



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