

NEW YORK STATE BAR ASSOCIATION

# *LEGALEase*

HIV/AIDS  
and the Law





## Introduction

HIV (Human Immunodeficiency Virus) is a virus that attacks the immune system, the part of the body that fights infections and other illnesses. HIV may be transmitted by all forms of sexual intercourse without barrier protection, by exposure to blood, blood products or certain other body fluids (such as semen, vaginal fluid and breast milk), by sharing needles (as in injection drug use) or when there is a traumatic injury from a source contaminated with the virus (such as a needle stick injury with a used needle from a person with HIV infection). Casual contact with a person infected with HIV has not been shown to transmit the virus. Over time, the immune systems of most people infected with HIV weakens making them more susceptible to life-threatening infections. AIDS (Acquired Immune Deficiency Syndrome) is a late stage of HIV disease.

This pamphlet is intended to advise you of your rights and to provide you with some general information and resources specifically related to issues that affect individuals with HIV or AIDS, or those who are perceived to have HIV or AIDS (or in some circumstances, those who associate with those having HIV or AIDS) who may have been discriminated against in the workplace. Although this information is current as of the date of this publication, it is subject to change as a result of court decisions, legislation and medical research. It is recommended that you seek up-to-date information from your attorney or any other resources listed at the back of this pamphlet. Please keep in mind that many of the statutes discussed require the filing of complaints with administrative agencies to preserve your rights. It is imperative that you consult with an attorney if you believe you have been discriminated against.

## Testing

A person infected with HIV can live without symptoms for many years. Thus, the only way to know if you are infected is to get tested. There are many benefits to being diagnosed early with HIV. Getting linked with medical care and social services can help you stay healthy and live longer. Knowing your status can also help prevent further transmission of the disease. To encourage testing, New York law now requires that most health care providers offer an HIV test to any patient 13 years and older (or younger if there is evidence or risk activity). Testing is not mandatory – it's up to you to decide whether you want to be tested –

but an offer must be made. If you are under the age of 18, you do not need your parent's permission to get tested so long as you understand the test and its consequences and have the ability to make an informed decision to consent. For a rapid HIV test (one that produces results within an hour), patients other than inmates in correctional facilities can consent simply by telling the provider that they want the test to be performed. Due to 2014 amendments to New York's Public health law, written consent is no longer required for an HIV test unless you are in a correctional facility. However, oral consent is necessary each time an HIV-related test is ordered. That consent is valid until revoked. To get your consent, medical personnel must, at a minimum, notify you of the test and give you an opportunity to decline. All HIV-related testing (and your consent for it) must be documented in your medical record. If you wish to be tested without giving your name, you can be tested anonymously at various public testing centers throughout the State.

The law requires that before anyone is tested for HIV he or she must be informed about the disease and potential ramifications of having it and/or a positive HIV test, or a negative test result (such as, the window period before the HIV test becomes positive in someone who is recently infected), as well as about ways to reduce the risk of transmission. This information can be discussed in person, or given to patients through other means like written pamphlets or videos played in waiting rooms. Most HIV tests detect antibodies, which are created by the immune system in reaction to HIV, in the blood rather than the virus itself. A "positive" screening test may mean that your blood shows evidence of antibodies to HIV, and a second, more specific, test will have to be performed on the same blood sample to ensure that a "false positive" test result did not occur.

When receiving the results of your testing, you will be counseled about the disease and its ramifications if your result is positive. If the test is negative, you must still be given information about high risk activities.

## **Confidentiality**

The federal Health Insurance Portability and Accountability Act (HIPAA) generally makes medical information private. New York law grants you additional protections if your medical records contain information about HIV, AIDS or an HIV-related condition.

You are entitled to your HIV-related information at any time. Subject to certain exceptions, your written specific consent is required before HIV-related information can be released to another person. Some exceptions where information can be released without your written consent are:

A person authorized by law who consented to the test for you; A health care facility (such as a hospital, blood bank or laboratory) or a health care provider (such as a physician, nurse or mental health counselor) giving care to you or your infected child, and anyone working for such a facility or provider who reasonably needs the information to supervise, monitor or administer a health service; Select government agencies involved in health, social services, and corrections; Insurance companies and other third party payers, such as Medicaid, if necessary for the payment for services to you.

New York State criminal procedure laws permit a court, when requested by a victim, to order HIV-related testing of persons who have been indicted or convicted of certain felony sex crimes that include sexual intercourse as an element. These laws permit the victim to be informed of the test results. HIV-related testing also may be ordered in certain circumstances when an individual, accused of a sex crime, pleads guilty to a lesser felony if the defendant admits to having unprotected sex with the victim.

In addition, a court may in rare instances order that HIV-related information be disclosed to protect the health of an individual or the public, or when there is a compelling need for the information in a pending criminal or civil legal action. Except when the disclosure is needed because someone else is in imminent danger, you must be notified of any application to order the release of your information and given an opportunity to oppose it.

Any HIV-related information that is sent to others must contain a statement prohibiting the receiving party from disclosing this information to any other party without your specific written authorization.

A list of the persons or agencies to whom confidential HIV information has been released must be noted in your medical record. Upon request, you must be informed of the parties to whom the information has been disclosed.

## **Names Reporting and Partner Notification**

Health care providers and professionals are required by law to report the names of all individuals who are diagnosed with HIV, AIDS or an HIV-related illness, other than those tested anonymously, to the Department of Health and County Health Officer. The law requires the Department of Health or the County Health Officer to contact the individual diagnosed with HIV infection, HIV-related illness or AIDS in order to identify the individual's contacts. Although you are not required to cooperate, if you identify known sexual partners who are at risk of infection, the Department of Health or County Health Officer will contact them and advise those persons that they may have been exposed to HIV. Your name cannot legally be disclosed to any of your partners. Health officials will only tell your partners that they may have been exposed to HIV, encourage them to be tested and inform them about the nature of the disease and options for treatment.

## **Insurance Companies**

A life insurer may test applicants for HIV antibodies and may reject those who are infected. In addition, under current law, your refusal to take a test may result in your not getting life insurance coverage. You must be advised about the test, its purpose, that a positive test indicates that you may develop AIDS in the future, and that you should consider further independent testing for confirmation of results. You are also entitled to be notified if an insurer rejects your application or offers to provide insurance at higher than standard rates, in whole or in part, due to results of an HIV antibody test. Providers of life, health and disability insurance may not test any specific population identified in a discriminatory manner, such as by marital status, lifestyle or zip code.

Under New York law, a health insurer or a health maintenance organization (HMO) may not test applicants for the presence of HIV antibodies or ask any medical questions of persons who apply for individual coverage or who are in small groups (50 or fewer). However, there may be a waiting period before coverage begins for pre-existing conditions. Health insurers may test applicants in larger groups. If you are currently covered by a health insurer and seek to change insurance companies, you should

consider such a change with great care and consult an insurance expert if you are HIV-positive, because the new policy may not cover pre-existing conditions for a period of time. If you are rejected, you may wish to contact the New York State Department of Insurance or its AIDS Hotline for information regarding possible alternatives. As of January 1, 2014, the Patient Protection and Affordable Care Act (PPACA) prohibits the denial of health insurance based on pre-existing conditions. PPACA also prohibits health insurers from charging higher premiums due to an individual's health status or medical conditions. If you do not have employer-based insurance coverage or cannot afford your insurance premiums, you may be eligible for Medicaid or tax subsidies.

Many self-insured employer health plans are governed by federal law and thus are not governed by the strict protection of this state. Therefore, state protection may not apply to you in terms of coverage, caps and premium changes.

## Housing

Persons living with HIV or AIDS may face discrimination in obtaining housing. Federal and state laws and municipal and city ordinances and regulations bar discrimination against persons with disabilities, including persons with HIV or AIDS, in the sale or rental of dwellings. An "aggrieved person" may file a complaint with a federal, state or local administrative agency or commence a court action.

Under certain circumstances, non-marital partners or non-traditional family members may have succession rights to apartments after the death of the prime tenant. A lawyer or legal services provider on HIV-related matters can advise you on this topic.

As a result of the burdensome cost of medical care and the loss of employment income, affording adequate and appropriate housing has become a major problem for many persons with HIV or AIDS. Depending on your income and financial resources, you may be eligible for government rent subsidies from the New York City HIV/AIDS Services Administration (for New York City residents) or the Public Assistance program administered by your county of residence. Contact these agencies for information on eligibility. In addition, if you are living on a fixed income, a number of nonprofit organizations

have created supported housing programs and independent living facilities with supplementary medical and social services.

## Home Care

An overwhelming burden of AIDS or HIV-related illnesses can be the cost of home care. Without home care, many may be unable to remain in their homes, yet home care costs can be prohibitive. The Medicaid program is available to meet these needs for those without private insurance or sufficient resources. Medicaid, the public assistance program administered by county social services departments, pays the medical expenses of those eligible for its coverage and has an extensive home care component which can range from part-time help a few hours a week to registered nurses around the clock. The Department of Social Services is required to provide Medicaid applicants with the range of services available through Medicaid. There are several levels of care for which a person may qualify, and the applicant may need to ask for a full explanation of benefits available. For those without private insurance who are not eligible for Medicaid, there are “ADAP” and “ADAP-Plus” (AIDS Drug Assistance Programs) which cover primary care and home care services to some degree.

## HIV/AIDS in the Workplace

Employees or job applicants who are infected with HIV or who are perceived as being infected with HIV are protected under federal and state law and municipal and city ordinances and regulations from acts of employment discrimination on the basis of their actual or perceived HIV infection.

## Federal Law

### Rehabilitation Act of 1973

The Rehabilitation Act prohibits discrimination based on disability in the areas of employment and the provision of services or benefits by any program or activity of an entity receiving federal financial assistance. This section provides, in part, that no “otherwise qualified” handicapped individual shall be excluded from participation in or be denied the benefits of any such program or activity. Equal Employment Opportunity Commission (EEOC) regulations define an “otherwise qualified” person with a handicap as one who, with or without reasonable accommoda-

tion, can perform the essential functions of the job without endangering the health and safety of himself or herself, or others. A “reasonable” accommodation is one that does not place an undue hardship on the employer. The courts have held that having AIDS or being HIV-positive, as well as the perception of being HIV-positive, are all considered handicaps for the purpose of protection under this statute.

## Americans With Disabilities Act (ADA)

The ADA sets a national mandate and provides uniform standards for addressing discrimination against people with disabilities in a number of areas: private employment, public services, telecommunications and public accommodations. The law complements the Rehabilitation Act and incorporates many of the same definitions and standards. The significance of the ADA is that, unlike the Rehabilitation Act, its coverage is not limited to federal contractors or recipients of federal financial assistance.

Instead, all employers with 15 or more employees are covered. HIV-infected individuals are covered by the ADA in the same manner that they have been covered by the Rehabilitation Act. Under the ADA, a “qualified individual with a disability” is defined as an individual who “with or without reasonable accommodation, can perform the essential functions of the employment position.” The ADA also extends protections to persons without disabilities if they have a known relationship or association with a person with a disability. A charge of discrimination must be filed with the EEOC to preserve your right to sue. The EEOC will investigate your complaint at no cost to you.

## Family Medical Leave Act (FMLA)

Generally, the law guarantees eligible employees the right to take unpaid leave from a job for family or medical reasons. FMLA affects private employers who, within a 75-mile radius of the employer’s work site, employ 50 or more persons for each working day, for each of 20 or more calendar work weeks in the current or preceding calendar year. FMLA requires covered employers to provide eligible employees with an unpaid leave of up to 12 weeks in any 12-month period for a variety of health-related reasons, including the birth or adoption of a son or daughter, or the care of a son, daughter, spouse or parent of the employee with a serious health condi-

tion, or because the employee has a serious health condition that prevents the employee from performing the functions of his or her position. There appears to be little doubt that someone with HIV will have a serious health condition as defined by the Act.

An eligible employee must have been employed by the employer for at least 12 months and for at least 1,250 hours during the prior 12-month period. The law does not require paid family or health leave. Leave may consist of paid leave, but the discretion to provide paid leave is left to the employer. Moreover, an employer can require that any leave based on a serious health condition of the employee or of the employee's family be supported by certification by a health care provider. An eligible employee who takes leave is generally entitled to be restored to his or her old job or to an equivalent position with equivalent pay and benefits. Employment benefits, which may have accrued to the employee prior to the date of leave, cannot be lost or taken from the employee.

## Occupational Safety and Health Act (OSHA)

In 1991 OSHA published rules on occupational exposure to blood-borne pathogens in order to improve "occupational safety" in the care of patients infected with blood-borne pathogens (for example, HIV, Hepatitis B and Hepatitis C). OSHA prohibits the discipline or discharge of an employee who refuses to work because of a reasonable fear of immediate serious injury. Under OSHA, employees face significant health risk as a result of occupational exposure to blood and other potentially infectious body materials because those materials may contain blood-borne pathogens such as HIV or Hepatitis B. Employers are required by OSHA to develop an Exposure Control Plan specific to the workplace.

The Exposure Control Plan is a guiding document to direct the specifics of the incorporation of the blood-borne pathogen standard and outlines policies and procedures related to blood-borne pathogen control within the workplace. The Exposure Control Plan requires universal precautions, engineering and work practice controls, personal protective equipment, housekeeping and waste removal procedures, Hepatitis B vaccination, post-exposure evaluation and follow-up, and employee training and record-keeping requirements. All employers were required to be in full compliance with the blood-borne patho-

gen standards. Employers failing to adhere to OSHA standards are subject to substantial fines and other sanctions.

## Employee Retirement Income Security Act (ERISA)

HIV-infected patients can face staggering medical costs while combating the effects of their illness. The potential impact of these costs on insurance rates has led employers to question whether an HIV-infected employee may be denied insurance coverage or simply terminated in an effort to avoid these additional costs.

ERISA prohibits an employer from taking action against an employee which is designed to deprive him or her of benefits under ERISA-protected plans. Inasmuch as health insurance is clearly an ERISA benefit, any attempt to deprive an individual of a health insurance benefit because of the cost associated with his or her illness is unlawful.

## Title VII of the Civil Rights Act of 1964

Title VII prohibits discrimination in employment on the basis of sex, religion, national origin, race and color. Acts or practices which disproportionately affect persons in these protected categories, as well as intentional acts of discrimination directed at these protected groups, are prohibited. Title VII has not yet been interpreted so as to provide protection to employees or prospective employees suffering from, or perceived as susceptible to, HIV infection.

Nonetheless, a blanket policy aimed at excluding from employment those infected with HIV, while neutral on its face, could impact disproportionately on certain categories of individuals, including, for example, homosexual men, people of color and certain nationalities. Consequently, a claim under a disparate impact theory might be stated against such a policy to the extent any of these three groups constitute a protected class. Title VII extends only to race, gender and national origin discrimination and is inapplicable to sexual orientation discrimination.

## State Law

### New York Human Rights Law (NYHRL)

The NYHRL prohibits covered employers and other entities from discriminating against individuals on the basis of “disability.” A disability is defined as “a

physical, mental or medical impairment resulting from anatomical, physiological or neurological conditions which prevents the exercise of a normal bodily function or is demonstrable by medically accepted clinical or laboratory diagnostic techniques, provided, however, that in dealing with employment, the term shall be limited to physical, mental or medical conditions which do not prevent the complainant from performing in a reasonable manner the activities involved in the job or occupation sought.” HIV infection has been judicially recognized in New York as a disability. The NYHRL also requires that the employer provide a reasonable accommodation. If you believe you have been discriminated against due to HIV status, you may wish to contact the New York State Division of Human Rights. Regional phone numbers are listed in the Resource section at the back of this pamphlet. The Division of Human Rights does not charge a fee for its services.

## Unprofessional Conduct and Licensure Issues — Health Care Professionals

Under New York State law, health care professionals licensed by the State Education Department may be subject to unprofessional conduct proceedings and may have their professional licenses suspended, limited or revoked for failing to observe infection control techniques in the practice of their profession. Included among those who are subject to professional sanctions are physicians, nurses, dentists, physical therapists, respiratory therapists and physician’s assistants. The State licensure provisions are intended to protect patients from infection and protect employees from exposure to infection.

State licensure renewal requires documented training in the following: the responsibility to adhere to accepted principles and practices of infection control; monitoring the infection control practices of those for whom the professional is responsible; strategies for prevention and control of transmission of disease-causing organisms; use of engineering and work practice controls; selection and use of barriers and/or personal protective equipment; principles and practices for disinfection and sterilization; and prevention and control of infectious and communicable diseases in health care workers. State public policy dictates that employees who follow proper infection control procedures and adhere to universal precautions may, in most instances, continue to work virtually without regard to their own HIV status.

## Other Laws

### Administrative Code of the City of New York

The Administrative Code of the City of New York follows the NYHRL and makes it unlawful to discriminate against any person with a disability, including those with HIV infection. This law also protects from retaliation those who report such discrimination, file claims to recover losses, or testify against the parties violating these laws. As is the case under the New York Executive Law, if you believe you have been discriminated against due to HIV status, the New York City Commission on Human Rights can determine whether your rights have been violated. Refer to the Resources section of this pamphlet to obtain the phone number. The New York City Commission on Human Rights does not charge a fee for its services.

### Sexual Orientation Non-Discrimination Act (SONDA)

SONDA prohibits discrimination on the basis of sexual orientation in housing, employment, credit, education, and public accommodation and services. An individual diagnosed with HIV or AIDS who is discriminated against on the basis of his or her sexual orientation will have the same legal recourse as an individual who is seeking protection under the NYHRL.

### Contractual Rights

An HIV-infected worker covered by a collective bargaining agreement may also find protection from unwarranted dismissal or other adverse employment actions through the arbitration process typically found in those labor agreements. At least one arbitrator has ruled that HIV infection is not, by itself, sufficient basis for terminating an employee under a contractual “just cause” provision if the employee is otherwise physically capable of performing his or her job. Such a termination would also be a violation of the Americans with Disabilities Act.

## Returning to Work

Based on current medical advances many individuals with HIV-related illnesses are now able to return to work. When one returns to work after an extended absence due to illness, concerns necessarily arise regarding the potential loss of government and pri-

vate disability benefits. The primary government benefits provided by the Social Security Administration (SSA) to people who have HIV or AIDS include Social Security Disability Income (SSDI) and Supplemental Security Income (SSI). SSDI is provided to people who have worked and paid Social Security taxes over a period of time, while SSI is a means-based entitlement, provided to people without a substantial work history.

The SSA has a number of special rules, called “work incentives,” that provide cash benefits and continued Medicare and Medicaid coverage. These incentives are particularly important to people with HIV disease who, because of the recurrent nature of an HIV-related illness, may be able to return to work following periods of disability.

The rules differ for SSDI and SSI. For people receiving SSDI, the benefits include a nine-month “trial work period” during which earnings, no matter how much, will not affect benefit payments, and a three-year guarantee that, if benefits have stopped because a person remains employed after the trial work period, a Social Security check will be paid for any month’s earnings below the “substantial” level (usually around \$1170). Additionally, Medicare coverage extends through the three-year time frame after the trial work period, even if an individual’s earnings are substantial.

SSI work incentives include continuation of Medicaid coverage even if earnings are too high for SSI payments to be made, help with setting up a “plan to achieve self-support” (PASS), and special consideration for pay received in a sheltered workshop so that SSI benefits may continue even though the earnings might normally prevent payment.

Many individuals also may be covered by long-term disability (LTD) insurance plans. Whether one receives benefits under a group or individual LTD plan, it is important to carefully read the summary plan description in order to understand the effects of returning to work. Many plans no longer pay any benefits when one returns to work, while some plans offer a partial or residual benefit.

Since individual financial circumstances, covered disability and insurance plans, prior work history, and benefit eligibility may radically differ, it is strongly encouraged that you speak with the Social

Security Administration regarding the impact of government-sponsored benefits and health care upon your return to work, and consult an attorney regarding the effect that your return to work will have on your private disability insurance.

The federal Ticket to Work and Work Incentives Improvement Act of 1999 provides SSD recipients who want to return to work with greater access to rehabilitation services and public health care benefits (including extensions of Medicare coverage). The SSA has prepared several summaries and a question-and-answer document concerning the law, which are available on its website, [www.ssa.gov](http://www.ssa.gov).

## **Other Discrimination**

New York State laws and New York City regulations make it illegal to discriminate against any disabled person, including individuals with HIV infection. You may not be discriminated against in your job; housing; places of public accommodation such as restaurants and theaters; applications for loans or credit; medical, legal and dental services; and other personal services available to the general public.

If you believe you have been the victim of discrimination due to HIV status, you may wish to contact the Equal Employment Opportunity Commission, the New York State Division of Human Rights, the New York City Commission on Human Rights, or a private attorney to determine whether your rights have been violated (see website information at the end of this pamphlet). Please be advised that the statute of limitations for filing this type of claim is extremely short. It commences from when you know or should have known that you have been discriminated against. Accordingly, it is imperative that you contact one of the above-referenced agencies or a private attorney immediately. Neither the Equal Employment Opportunity Commission, Division of Human Rights, nor the Commission on Human Rights charges a fee for its services, and all of these agencies can investigate your complaint.

## **Childbearing**

A fetus may become infected with HIV during pregnancy or childbirth if his or her mother is HIV-positive. All infants born to HIV-positive mothers test positive at birth, yet only about 20% of those infants are actually HIV-infected. The infection rate in babies is lower if the mother is treated with HIV drugs dur-

ing pregnancy (as low as 2%). This is because the initial test only indicates the mother's HIV status, not that of the newborn. Most infants will revert to HIV-negative status once their own immune systems develop. It is also possible for an infant to become infected with HIV after birth if no intervention prevents an HIV-infected mother from breast feeding her child.

In order to help infants who are, or may become actually HIV-infected, either prenatally or postnatally, the New York Legislature in June 1996 added HIV to the list of conditions for which newborns are automatically screened. Thus, mandatory HIV testing of all newborns was instituted. When a newborn tests HIV-positive it means the mother is definitely HIV-positive. It is hoped that when mothers are informed of HIV-positive results, they will take positive steps to prevent transmission of infection by avoiding breast-feeding and to seek medical care for themselves. Mandatory testing of newborns, however, does not address the issue of preventing HIV infection prenatally. Study results show that treating HIV-positive pregnant women with combination anti-retroviral medication (usually 3 drugs) during pregnancy substantially reduces the risk that their infants will be born infected. Thus, it is extremely important that women who are pregnant or considering pregnancy receive counseling concerning the benefits of voluntary HIV testing, and they should request HIV testing as early as possible.

## **Vertical (Mother-Baby) Transmission of HIV**

More recently, the use of combination anti-retroviral therapy has become the standard of care for people with HIV/AIDS. It is now accepted that pregnant women should take this combination therapy during pregnancy, rather than AZT alone.

Elective caesarian section at 36 weeks has also been shown to reduce the risk of HIV transmission from mother to baby by 50% compared to spontaneous vaginal delivery in women with high viral loads (the amount of virus measured in the mother's blood). This option is now recommended by the American College of Obstetrics and Gynecology.

Earlier diagnosis of HIV infection in children born to HIV-positive mothers is now possible. The HIV-

DNA assay uses the polymerase chain reaction (PCR) method. This test can determine the HIV status of the infant and distinguish it from the mother's HIV antibody, allowing the diagnosis of HIV infection in the infant to be made at birth.

Another promising area of research investigation involves sperm washing techniques for males who are HIV-infected. Sperm-washing separates sperm from the surrounding fluid, in which most of the virus is believed to reside, and the sperm is then used to fertilize the egg, using in vitro fertilization techniques.

## Parenting

HIV-infected parents of minor children and single parents in particular may want to make advance arrangements for the care of their children. Section 1726 of the Surrogate's Court Procedure Act (SCPA) allows a person who is at risk of becoming incapacitated or dying to petition the court for a "standby guardian" whose authority commences upon the parent's death or incapacity. This section allows the parent to name the guardian of his or her choice through either a court proceeding or a witnessed, notarized document. The guardianship does not terminate parental rights or custody, but allows the standby guardian time to file for custody if the parent dies or becomes incapacitated. If a parent changes his or her mind about the choice of a guardian, he or she can revoke the designation. It is hoped that this law will permit improved stability for the children facing the loss of their parents while it enables parents to feel secure that their children will be cared for by the individual(s) they choose. The law was written to be "user friendly" and takes into consideration the limitations imposed on a parent by an incapacitating illness. Legal assistance is needed to establish the standby guardianship.

## Matrimonial

In New York State, no court has held that a divorce may be granted merely because one of the parties is HIV-positive or has AIDS. In addition, except for extreme or "shocking" conduct, marital misconduct is generally not relevant to property division in divorce. Fault, however, may have some limited bearing on the issues of maintenance and support. There are no court decisions that have directly addressed the issues of HIV/AIDS status in deter-

mining fault. In 2010, New York adopted a “no-fault” divorce option that allows parties to divorce if the marriage has been irretrievably broken for 6 months. A judge will determine custody and visitation of children according to the “best interest of the child” standard. Some factors a judge may consider are whether a parent is physically and mentally able to care for the child, whether the parent has adequate housing for the child, and whether the parent is capable of providing sufficient nurturing and support for the child. There are no court decisions denying custody specifically because of HIV/AIDS status. An HIV-infected parent may be granted custody and/or visitation rights. State law permits the disclosure of HIV-related information to the child’s court-appointed attorney, also referred to as the Attorney for the Child.

## Planning for Your Future — Health Care Proxies

Because of advances in treatment, people with HIV are living longer. For many, HIV now is a chronic lifelong illness that can be controlled with medications and healthy lifestyle choices. Nevertheless, if you have AIDS or are HIV-positive, you may want to designate a friend or family member to be your health care agent. You should pick a person that you can trust and with whom you have discussed your health care wishes. Your health care agent can make health care decisions for you in the event that you become unable to make such decisions for yourself. Forms, called health care proxies, used to appoint a health care agent are available on the NYS Department of State website, at health care facilities, and elsewhere, but there is no requirement that you use a specific form. All that is required is that you do the following things in writing:

- Name the person (at least 18 years of age) whom you want to act as your agent.
- State that you want your agent to make your health care decisions in the event that you become unable to make them for yourself.
- Sign this writing.
- Write the date of this writing, and have two people who are not the agent and are at least 18 years old sign as witnesses to your signature.

Your proxy also may incorporate your directives concerning the type of health care you want or the type of health care you want to decline. Such a statement can then be used as evidence of your wishes. However, it is important that you thoroughly discuss with your health care agent your wishes, in particular those related to nutrition and hydration. If you wish for your health care agent to make decisions concerning your nutrition and hydration, it's helpful to include a statement in your proxy indicating that your agent knows your wishes with respect to nutrition and hydration. Your Health Care Proxy will be recognized in most states.

## Living Wills

If you cannot find a trusted friend or family member to act as your health care agent you can still create a document that states your wishes concerning the health care you want and the care you choose to decline. That document is a Living Will. Although the document can provide clear evidence of your health care wishes within the specific instances stated in the document, the Living Will does not authorize any particular person to act on those wishes. If you execute a Living Will, consider executing one every few years even if your views do not change. This avoids a challenge that you may have changed your views since you executed the document. In New York State, it is preferable to appoint a health care agent, if one is available, because such an agent can act on your behalf in making all health care decisions, not just those specifically discussed by you and because you can decide who that agent will be instead of leaving that decision up to the court.

Thoroughly discuss your directives with your life partner, family, friends, medical providers, and clergy. Let them know your firm views. Engage them to be your advocates when you cannot express your own wishes.

## Nomination of Guardian

A court may appoint a guardian for you if you are mentally or physically incapacitated. You may also petition the court to determine a guardian if you are unable to care for your needs. A guardian's role may include meeting your personal care, financial, and health care needs. The guardianship lasts only so long as the court determines that you need the protection. You have a right to be represented by an

attorney during guardianship proceedings and, if you propose a guardian, most courts will honor your request. Having a durable power of attorney (described in the segment below) may be a better alternative because it allows you to select the best person to manage your personal and property needs.

## **Power of Attorney**

A power of attorney is a document to delegate authority to someone else — an agent — to act for the individual, as in times of disability or illness. The authority can be broad or limited, as appropriate. You can provide for the management of your financial affairs through a power of attorney given to a trusted friend or family member. You grant your agent authority only for those activities you designate by your initials. You can elect to use a durable power of attorney, which is the kind that continues even should you become mentally incompetent or physically not able to make decisions.

For more information on Health Care Proxies, Living Wills, Powers of Attorney, and similar documents, refer to the New York State Bar Association pamphlets entitled “Living Wills and Health Care Proxies” and “Why You Need a Will.”

## **Funeral Plans**

Discuss your wishes for funeral arrangements with your trusted friend(s) and family member(s). You have the right to direct the disposition of your remains. In the absence of expressed wishes, your next-of-kin, even if estranged or if you have not had contact, control the funeral and burial. For an unmarried person without adult children, this is usually your parents or brothers and sisters. A close friend will not be recognized to make funeral arrangements unless that person can prove the wishes of the person who has died. It is therefore desirable to have a writing or direction to someone to make the arrangements. Some funeral homes will recognize the executor of the will when given the power in the will or similar document. To assure control over your funeral, you may want to consider prepaid arrangements for your funeral and burial. If it is your desire to be cremated, you may prepare and “Affidavit of Cremation” to ensure that your wishes are understood and followed.

## Estate Plans

It is wise to have a will, which needs to be drafted by a lawyer. A will allows you to decide who receives your property or money after your death. If you do not have a will, a judge will decide who receives your property.

To make a will, you must have the legal mental capacity to understand what your estate consists of, who your loved ones are, and the effect of making a will at the time that you sign the document. Even though you might suffer bouts of dementia related to your illness or the medications that you take, you may still make a will if your mind is sufficiently clear at the time that you make the will.

Avoid using hospital personnel to witness your will. Many hospitals prohibit staff from witnessing wills or impose onerous conditions on their use. Witnesses may be called by the court to be questioned. In fact, do not postpone making your will until the end is near. If you are single, your need for a will is greater than that of married people. You should have a will long before you face a medical crisis.

For more information on developing estate plans, refer to the New York State Bar Association pamphlet entitled “Why You Need a Will.”

## Making a Plan for Your Children

If you have children, it is critical that you create a custody plan for your children after your death, especially if your children’s other parent is not living in the household, is HIV-positive, or is already deceased. If you do not do this, your children may be placed in foster care with strangers. It is important that in making your plan, you consult with a lawyer who is knowledgeable about permanency planning.

Once you have chosen a proposed custodian, a first step is making a will in which you name that person your minor children’s guardian. It is often advisable to take other steps as well to ensure that your children go to the person whom you have chosen.

If you are ready to give up care and custody of your children now, you and your proposed caregiver can pursue custody, guardianship or adoption.

If you do not want to lose custody of your children now but wish to put a plan in place for the future, you can appoint a standby guardian. You may name a standby guardian now whose authority will not begin until your death, mental incompetency, or physical debilitation. You can provide for a standby guardianship by going to court or by signing a written, notarized designation. Going to court is time consuming but far more effectual than the signing of an out-of-court form, which is merely testamentary in effect. By choosing a standby guardian through the judicial process, virtually all of the legal work will have been completed prior to the need for a commencement of guardianship. If you live within the five boroughs of New York City and money might become a problem for the person whom you have chosen as your children's custodian, another permanency planning option is the Early Permanency Planning Program (EPP) of the Administration for Children's Services. In EPP, you place your children in voluntary foster care with a caregiver whom you have chosen and the caregiver receives resulting foster care subsidies and allowances for the care of your children. At this time, EPP is available only in New York City.

## Living Benefits

To fund health care expenses, living expenses or sometimes just a dream, people with a relatively short life expectancy may be able to cash in on their life insurance. Some issuers of life insurance include an accelerated benefits rider that allows the owner with an estimated life expectancy of about a year or less to apply to the issuer for payments of a percentage of the policy as if they had died. Currently, few issuers offer the benefit and those that do often limit the percentage that can be accelerated to one half the face value of the policy.

If a life insurance policy can be assigned for value, the owner of a policy on his or her own life can sell all or part of the policy to a third party for a payment that reflects the buyer's estimate of the seller's life expectancy, the face value assigned and interest rate assumptions. A sale to an unrelated third person is called viatication.

New York regulates viatication. Only companies that have applied for registration in New York can legally serve as agents or buyers of such policies. Those

companies must comply with regulations requiring disclosure to you of certain information, including whether your broker is receiving a fee for the service. Delivery of documents and payment of the purchase price must be through an escrow agent. Despite regulation, New York residents still get offers from viatical settlement companies that have failed to comply with New York regulation. It is wise to have an attorney review your viatical settlement arrangements. Federal tax law made such payments tax-free in limited circumstances if received after December 31, 1996. Amounts received by New York residents from viatical settlement companies not registered in New York are subject to federal income tax.

No one, not even your creditors, can force you to viaticate insurance policies on your life. If you choose to viaticate a life insurance policy, your dealings with a regulated viatical settlement company are confidential. Working with a registered viatical settlement company does not require public disclosure of your HIV status.

## **Resources and Referrals**

The following information is intended to be used as a reference guide in the event you require additional information about the provisions contained in this pamphlet, or if you require the assistance of an attorney or other professional. The organizations listed are not intended as a complete list of available resources. We recommend that you contact your local bar association or attorney referral service if you have a legal question pertaining to any of the information provided in this pamphlet. Please also refer to the following AIDS-related organizations who provide services to persons with HIV/AIDS.

## **U.S. Equal Employment Opportunity Commission**

[www.eeoc.gov](http://www.eeoc.gov)

## **NYS and NYC Human Rights Offices**

New York State Division of Human Rights

[www.dhr.ny.gov](http://www.dhr.ny.gov)

### **Counties covered**

Albany, Binghamton, Bronx, Brooklyn, Buffalo, Long Island (Naussau), Long Island (Suffolk), Manhattan, Peekskill, Rochester, Syracuse, and White Plains.

New York City Commission on Human Rights

[www.nyc.gov/cchr](http://www.nyc.gov/cchr)

## **CCHR Community Service Centers**

[www1.nyc.gov/site/cchr/community/community.page](http://www1.nyc.gov/site/cchr/community/community.page)

### **Counties covered**

Manhattan, Brooklyn, Bronx, Queens, and Staten Island.

## **Lawyer Referral Services**

New York State Bar Association Lawyer Referral and Information Service

[www.nysba.org/lawyerreferral](http://www.nysba.org/lawyerreferral)

### **Counties covered**

Allegany, Cattaraugus, Cayuga, Chautauqua, Chemung, Chenango, Clinton, Columbia, Cortland, Delaware, Essex, Franklin, Fulton, Genesee, Greene, Hamilton, Herkimer, Jefferson, Lewis, Livingston, Madison, Montgomery, Niagara, Oneida, Ontario, Orleans, Oswego, Otsego, Rensselaer, St. Lawrence, Saratoga, Schenectady, Schoharie, Schuyler, Seneca, Steuben, Tioga, Tompkins, Ulster, Warren, Washington, Wayne, Wyoming, and Yates.

## **Individual Lawyer Referral Services**

Albany

[www.albanycountybar.org](http://www.albanycountybar.org)

Broome

[www.bcbar.org](http://www.bcbar.org)

Dutchess  
[www.dutchesscountybar.org](http://www.dutchesscountybar.org)

Erie  
[www.eriebar.org](http://www.eriebar.org)

Monroe  
[www.mcba.org](http://www.mcba.org)

Nassau  
[www.nassaubar.org](http://www.nassaubar.org)

Onondaga  
[www.onbar.org](http://www.onbar.org)

Orange  
[www.orangecountybarassociation.org](http://www.orangecountybarassociation.org)

Putnam  
[www.putnamcountybar.org](http://www.putnamcountybar.org)

Rockland  
[www.rocklandbar.org](http://www.rocklandbar.org)

Suffolk  
[www.scba.org/new](http://www.scba.org/new)

Sullivan  
[www.scbany.org](http://www.scbany.org)

Westchester  
[www.wcbany.org](http://www.wcbany.org)

## **New York City Lawyer Referral Services**

Bronx  
[www.bronxbar.com](http://www.bronxbar.com)

Brooklyn  
[www.brooklynbar.org](http://www.brooklynbar.org)

New York  
[www.nycbar.org](http://www.nycbar.org)

Queens  
[www.qcba.org](http://www.qcba.org)

Richmond County Referral Service  
[www.thercba.com](http://www.thercba.com)

National Employment Lawyers Association Referral Service (NELARS)

[www.nelany.com](http://www.nelany.com)

## **AIDS Organizations**

AIDS Center of Queens County

[www.acqc.org](http://www.acqc.org)

AIDS Related Community Service

[www.hudsonvalleycs.org](http://www.hudsonvalleycs.org)

Albany Law School Health Law Clinic

[www.albanylaw.edu/centers/clinic-and-justice-center/clinics/health-law](http://www.albanylaw.edu/centers/clinic-and-justice-center/clinics/health-law)

Alliance For Positive Health

[www.allianceforpositivehealth.org](http://www.allianceforpositivehealth.org)

Bridging Access to Care, Inc.

[www.bac-ny.org](http://www.bac-ny.org)

Community Health Action of Staten Island

[www.chasiny.org](http://www.chasiny.org)

Gay Men's Health Crisis (Legal Services)

[www.gmhc.org](http://www.gmhc.org)

HIV/AIDS Services Administration

[www1.nyc.gov/site/hra/help/hiv-aids-services.page](http://www1.nyc.gov/site/hra/help/hiv-aids-services.page)

Legal Action Center

<http://lac.org>

Long Island Association for AIDS Care

[www.liaac.org](http://www.liaac.org)

*This pamphlet, which is based on New York law, is intended to inform, not to advise. No one should attempt to interpret or apply any law without the aid of an attorney. Produced by the New York State Bar Association Committee in cooperation with the Health Law Section.*





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