Written by: Jerome Ernst, MD, Jan Hufnagle, RPh, Stephen Karpiak, PhD, and Andrew Shippy, MA

Edited by: Mark Milano and Kai Wright

Associate Editors: Laura Engle and Luis Scaccabarrozzi

Graphic Design: Jedd Flanscha

Special thanks to Marjorie H. Cantor, Richard Havlik, MD, and the many individuals and organizations that offered input and guidance in the development of this booklet.

Funding for this booklet was provided by a grant from the M·A·C AIDS Fund and, in part, by the New York City Department of Health and Mental Hygiene.

230 West 38th Street, 17th Floor, New York, NY 10018
212-924-3934 FAX 212-924-3936

www.acria.org

The information in this booklet is presented for educational and informational purposes only and is not intended as medical advice. All decisions regarding a patient's personal treatment and therapy choices should be made in consultation with a physician. AIDS Community Research Initiative of America is solely responsible for the contents of this booklet. The statements and opinions expressed within do not reflect the views of any publication funder. The photographs in this booklet are for purposes of illustration only. The statements and experiences in these pages are not those of the models, and the use of their likenesses implies nothing about their health status, sexual orientation, or life history.

Daniel Tietz
Executive Director and Editor-in-Chief

Table of Contents

A Snapshot of Older Adults Living with HIV

In 2005, 1,000 people volunteered for an unprecedented ACRIA study designed to shed light on the unique needs of people over 50 living with HIV. In the study – called *Research on Older Adults with HIV*, or ROAH – 80% of volunteers were people of color and 33% were women, mirroring older people living with HIV in New York City. ROAH found that their concerns focused on the illnesses of aging, increased feelings of isolation from social support networks, and the negative impact of HIV stigma, shame, or ageism, which is discrimination based on age.

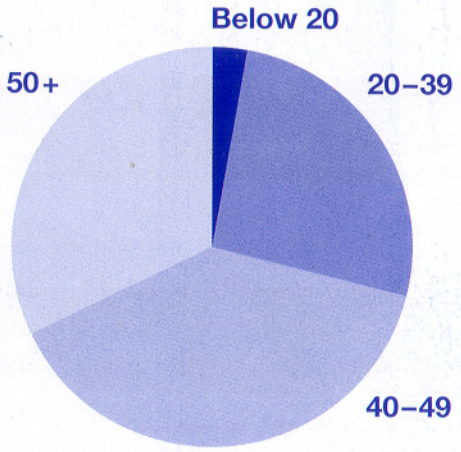
- Volunteers had been living with HIV for an average of 13 years, and while half had an AIDS diagnosis based on serious illness, only 13% had a CD4 count below 200. Nearly 85% were taking HIV meds.
- 67% self-identified as heterosexual, 9% as bisexual, and 24% as homosexual.
- 70% lived alone, which is double the number of all older New Yorkers.
- More than half of those who had used alcohol or drugs were in recovery. Over one-third continued to use recreational drugs or alcohol, and more than half smoked.
- Thirty-six percent had used injection drugs at some time.

ROAH and other research have found that older adults with HIV often lack the family and community support that can provide the care they will need as they age. This type of care is critical; about 44 million Americans currently act as caregivers to family and friends who have various illnesses. If this informal care were replaced by paid caregivers, it would cost more than $300 billion a year.

HIV and Older Adults

Until recently, few would have thought that people with HIV would become seniors. But thanks to striking advancements in HIV treatment, people with HIV are now living much longer. The number of older adults with HIV is today larger than ever – and the percent of people with AIDS over age 50 is now more than double that of people under 24.

Even though the success of HIV treatment is the main reason for this "graying" of the epidemic, one in every six new cases of HIV in New York City is found in people over 50 as well. It is likely that the majority of New Yorkers living with HIV will be over 50 years old within the next decade, and this trend is happening across the U.S. As the chart on the right shows, people over 40 make up 70% of all people with HIV in New York City.



We don't know all the unique challenges older adults with HIV will face, but we're discovering more every day. The effect of HIV on the aging process itself, for instance, is just beginning to be studied. We don't know if the major health challenges of aging – heart disease, diabetes, cancer, etc. – will occur sooner or more often as people age with HIV. It is critical that we learn more about these medical issues, since they are also common in those most affected by HIV in the U.S.: African-Americans, Latinos, and women.

We have much hard work to do to understand this epidemic.

Facing New Challenges

Most conversations about healthcare begin with the body, but wellness means taking care of the mind and soul as well. And people with HIV, particularly those who are aging, face a host of social challenges to emotional wellness. Perhaps at the top of that list of ills is the deadly disease of shame that persistent HIV stigma creates, and the difficulty that brings to the search for a life partner.

We formed a local brunch group that meets monthly, but because of the stigma, we go out of our area for the brunch. In spite of the support group, there are times of loneliness. My general feeling is that I am not interested in dating again, just finding a companion with whom I can talk and travel, someone who understands what it is like to live with HIV and be a senior.

—Sharon, 59

Creating a Life without Shame

Some stigma is born from ignorance. Despite what we've learned about HIV over nearly three decades, many people still don't understand how the virus is spread and what puts people at risk. Myths from the early days of the epidemic persist: that AIDS is a disease only of gay men or drug addicts, or that the virus can be spread by touching or kissing. These myths continue to create fear and stigma about the virus and the people who have it. But people get HIV through certain high-risk activities, not because of who they are or what group they belong to.

HIV stigma can be deadly. It often combines with racism, sexism, homophobia, and ageism to create barriers to the services people need. It can have a strong impact on health and well-being, and can cause older adults to become isolated and fearful and to avoid needed medical and social services. It can prevent them from reaching out to their families, churches, or community organizations for help, and it can reduce the effectiveness of HIV prevention efforts.

Stigma related to HIV is more common than that of most other health conditions. Fear of HIV is so powerful that it can extend to the families and friends of people with HIV, and even to their HIV care providers. Some people fear that disclosing their HIV status or insisting on using condoms will limit opportunities for sexual contact or lead to rejection or violence from partners. For other people, the negative reactions they experience may decrease their desire to stay healthy, including taking all prescribed medications on time.

Older adults with HIV may also experience ageist attitudes from service providers, friends, and family. This creates a double barrier to prevention, treatment, and care. Knowledge about HIV and aging can go a long way to reduce the stigma caused by the misinformation that is still too common.

Stigma's Toll on Older New Yorkers with HIV

Participants in ROAH – ACRIA's study of 1,000 people with HIV over age 50 – said they experienced high levels of stigma, and that the negative reactions of others were harder to accept than their own feelings of guilt or shame.

- Over half of the volunteers in the study said they do not receive support from their places of worship, mostly because of negative attitudes toward people with HIV.
- Only 46% had told all their family members they have HIV, and only 35% had told all of their friends.
- The adults in ROAH reported depressive symptoms five times more often than the general New York City population. About a third reported social isolation.

Telling It Straight:

I Was Stymied by Stigma

You know, stigma is a terrible thing. But people criticize you because they are angry at themselves; it's about what you know about yourself. You can be a long-term survivor, like me. I have four children and they're grown. They really don't talk about the virus to me, because I guess they look at me and they don't want to accept it. And I really don't get sick, so it's not a family conversation. But when they're ready, we'll talk about it.

Diane Smith, 59

Sexual Healing

One place that many people of all ages living with HIV feel stigma's sting is in the bedroom. The stress of disclosing HIV status, and the potential rejection that could – and too often does – follow that honesty, drives many people either to stick to positive sexual partners or to avoid sex altogether. A high number of the older adults living with HIV in ACRIA's study said they weren't sexually active. Still, a great many older adults are clearly choosing to remain sexually active – and that fact has crucial implications for those living with HIV.

The myth that sex is only for younger people remains strong. But the biological changes that happen when we age do not always include reduced sexual desire. Researchers have found that 60% of men and 38% of women over age 60 say they are sexually active. (The difference between men and women may be because women tend to live longer than men and are more likely to be widowed or without a partner.)

One study found that older adults who had sex at least once a month said that maintaining an active sex life was an important part of their relationships with their partners. Most said that they were at least as satisfied sexually as they had been in their 40s – about half of people aged 45-59 had sex at least once a week.

The older adults in this study said that being ill or on medication lessened sexual activity, and they reported that if their health were better, their sex lives would improve.

All of this means older adults face real risk for HIV transmission. Yet many, especially post-menopausal women, do not see themselves at risk for HIV or other STDs. As a result, they may be less likely to practice safer sex than younger people. Since erectile dysfunction medications like Viagra and Cialis can increase sexual activity, prevention strategies and safer sex messages that target older adults are needed.

Half of the volunteers in ACRIA's ROAH study said they had not had sex in the last three months. This may be due to the fact that 70% of them lived alone and that only 15% lived with their sexual partners. The stigma and repeated rejection that those living with HIV encounter may also play a part.

Over the Hill? Not Under the Sheets

A recent landmark study of 3,000 people confirmed that interest in sex does not fall off later in life – and if it does, it is usually due to poor health or to having no partner.

- 73% of people aged 57-64 reported having sex in the previous year, as did 53% of those aged 64-75 and 26% of those aged 75-85.
- Over 53% of the men reported having sex exclusively with women, 38% exclusively with men, and almost 10% with both genders.
- Among those who were sexually active, the majority reported having sex two to three times a month.
- If a person's health was very good, that person was twice as likely to be sexually active as those in poor health.

Sixteen percent of people in ROAH who said they were sexually active reported that they had unprotected anal or vaginal sex with a partner who was not known to have HIV.

While 28% of those who were sexually active said they would not have unprotected sex under any circumstance, 32% said that a desire for sex and an attractive partner might lead them to do so, and 32% said they might if the partner asked for it. ROAH volunteers offered numerous reasons for having unprotected sex – 27% cited being high on drugs, 19% said they felt depressed or needy, and 14% believed there was only a low risk of getting an STD. Almost half of those who were sexually active

Telling It Straight:

I've Been Singled Out

I don't know if it's my age or my medication, but I don't have much of a sex drive. Anyway, I like cuddling and being affectionate more than what you see on TV, where you get all worked up. I would love to date again … but I'm at the stage in my life where I want more than I found in the men I tried to date. My girlfriend says I've got high standards. Well, yeah. So, right now I really haven't found anybody that I want to spend time with.

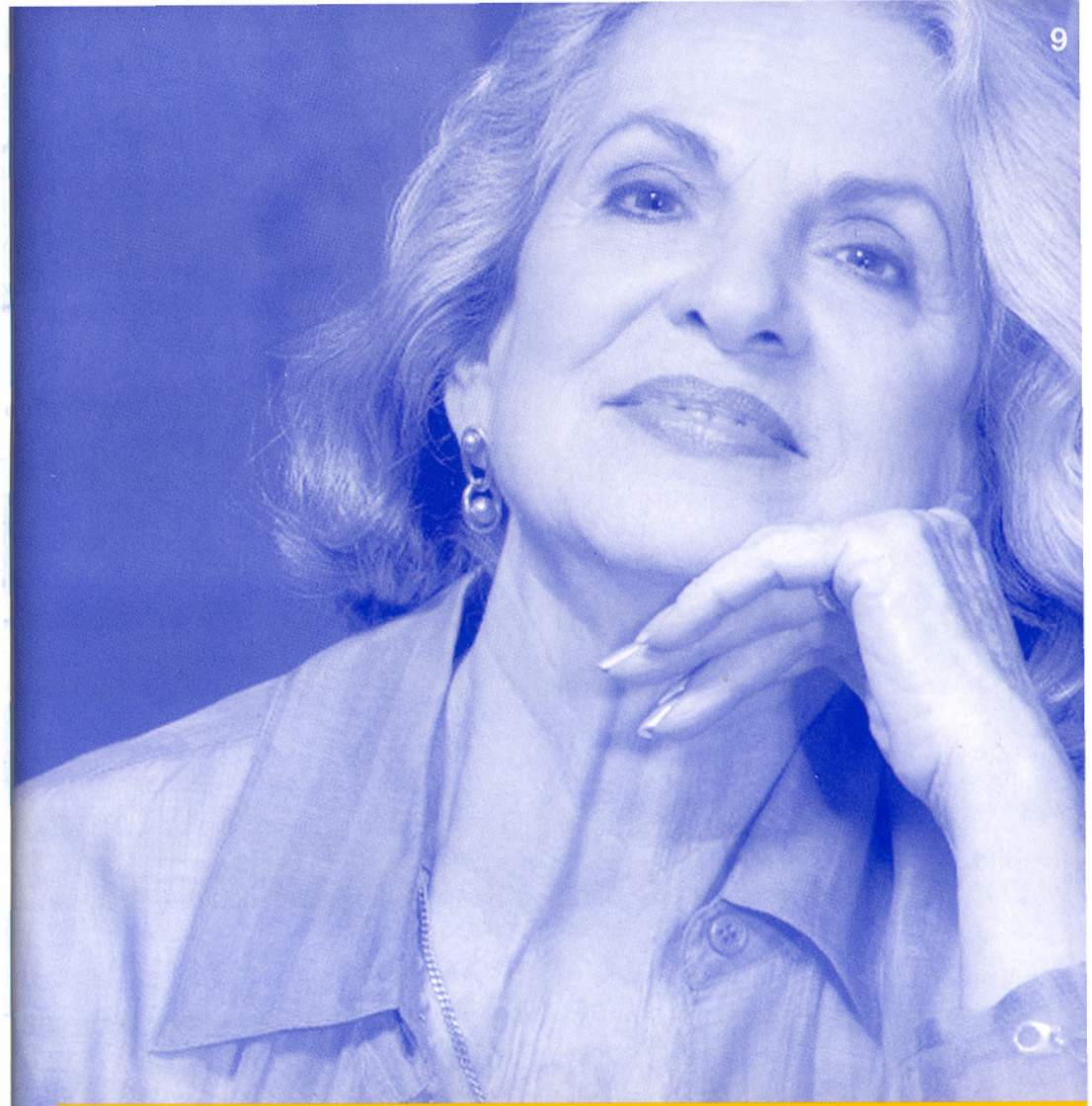
Patricia Shelton, 54

used alcohol or drugs with sex. And while the risk of infection with a second strain of HIV is still being debated, unprotected sex presents a clear risk of other STDs for people with HIV.

Use of drugs like Viagra was linked to an increase in unprotected sex among men with partners whom they knew to be HIV positive or whose HIV status was unknown. But these meds did not increase the incidence of unsafe sex when the men had sex with partners known to be HIV-negative.

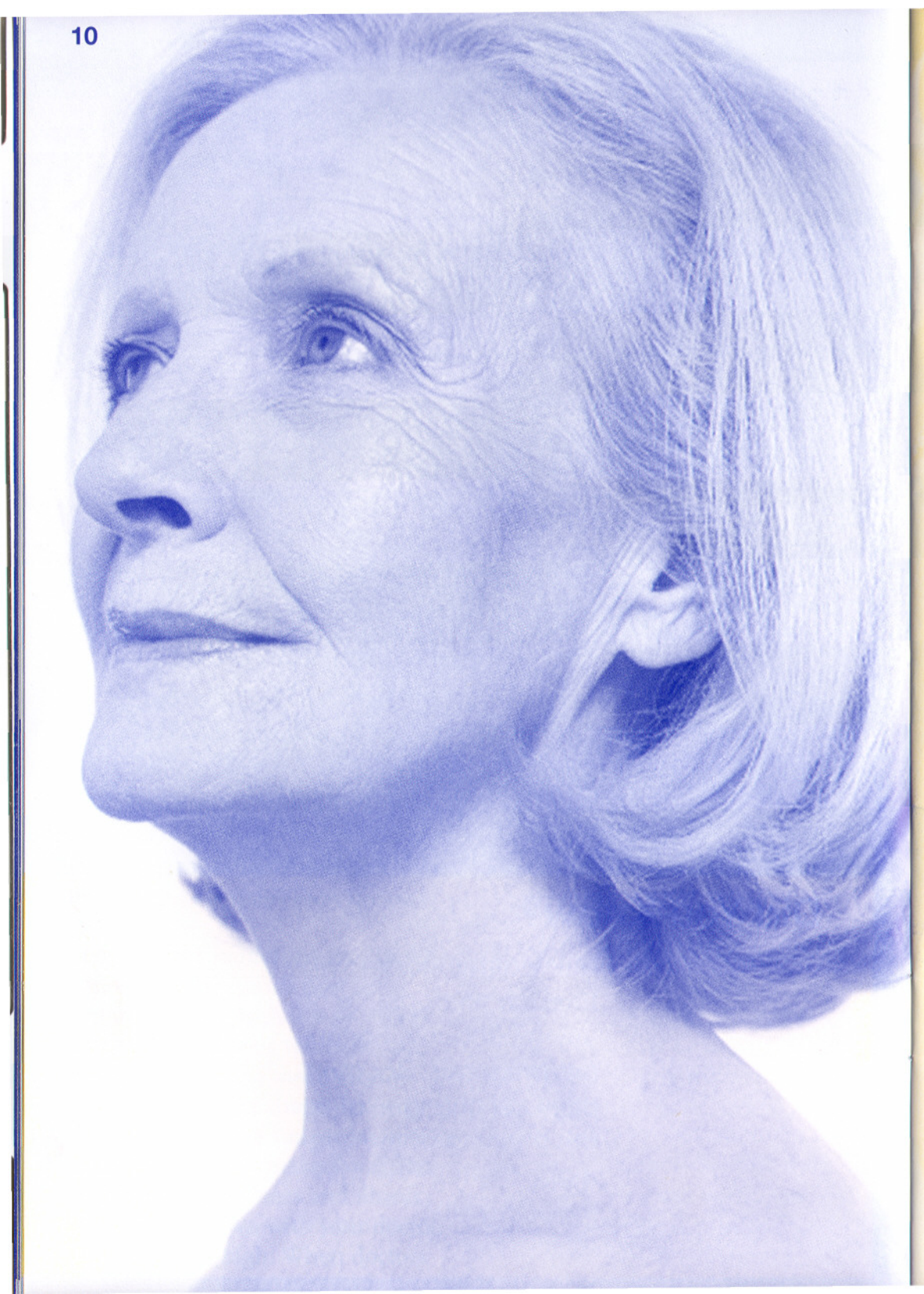
Despite all of these realities, many healthcare providers don't consider older adults to be at risk for HIV and other STDs. They may be less likely to talk to older adults about drug or alcohol use, or may be uncomfortable providing safer sex info to people who are older than they are.

That puts the burden on us – as we age, we've got to push past fears and insist our healthcare providers take our sexual lives seriously, too. Ask questions, and insist they be answered. Conversations that may be inappropriate or uncomfortable in other settings may make the difference between wellness and illness when sitting down with your doctor. The stakes are high: When doctors and patients fail to communicate about sexual health, it throws them off the path to diagnosing broader health issues properly. Many age-related illnesses share symptoms with HIV disease, so not talking about risk factors and HIV-related symptoms can lead to a wrong or delayed diagnosis of HIV or other STDs – and a dangerous lag in beginning treatment. In fact, older adults with HIV are more likely to be diagnosed late in disease than their younger counterparts.



Did You Know?

Many older women who have been through menopause do not insist upon using condoms because they can't get pregnant. But the truth is that the physical changes of aging – such as the thinning of the vaginal wall – can make them more vulnerable to STDs, including HIV.



Medical Matters

Once emotional wellness is addressed, you're ready to address old-fashioned physical health as well – and that can be complicated when also dealing with the aging process.

People living with HIV often learn a lot about keeping the virus at bay, and some even become "HIV experts," helping those newly diagnosed get educated, too. But living well with HIV takes more than just understanding how to keep track of HIV medications and lab reports. Aging leads to a variety of health challenges, some of which are complicated by HIV. The following pages contain a brief overview of some of the most common conditions people encounter as they age – and tips for staying a step ahead of them.

"If you don't know, learn; and if you do, teach."

Those words created hope for me, and brought opportunity. So I just started asking a lot of questions. I'm at this age now, and there's a lot of knowledge I've absorbed over the years, and I want to share it.

—Ed Shaw, 66

Health changes that are a normal part of aging can be similar to changes that happen in people with HIV. Fatigue, lowered immunity, skin conditions, and nutritional imbalances happen with aging but can occur in people with HIV regardless of their age. Some HIV drug side effects, like the loss of fat in the face and limbs, also occur in some people as they age. So in older adults with HIV, it can be difficult to pinpoint the cause of certain conditions and to find the best treatment.

Certain aspects of aging are obvious: thinning hair, wrinkles, loss of height, etc. None of us are surprised by the fact that our bodies change as we age; look in a mirror and that truth is clear. But changes are also happening inside that we cannot see or feel. These changes involve our internal organs, happen at different rates, and are different for each individual. They are affected by genetics, gender, medications, substance use, life stressors, quality of medical and social support, and other illnesses.

HIV is more common in poorer communities, among people of color, and in women, all of whom are also at higher risk for many age-related diseases. For example, African-Americans are more likely to have high blood pressure or diabetes. In addition, the racial and ethnic groups most affected by HIV are also those who face the most difficulty in obtaining healthcare. So as people with HIV age, they face the challenges of health risks from aging, drug side effects, and other diseases and conditions – HIV alone will not define their health.

It's not possible to list all of the biological changes of aging here. It's also important to remember that people age in different ways and at different rates. Most changes are gradual, almost unnoticed, while others can occur suddenly. Their causes fall into three basic categories: disease, inactivity or disuse, or aging itself.

Immune System

Since immune function declines with age, HIV disease can progress more rapidly in older adults. The thymus gland – which produces immune cells such as the all-important CD4 cells – begins to shrink early in life, and as a result the number of immune cells in our bodies decreases as we grow older.

It was once thought this meant it would take longer for CD4 cell counts to rise in older adults once they started taking HIV meds. But studies show that three months after older adults start HIV drugs, their CD4 counts increase and viral loads drop much the same as they do in younger people. (This may be the result of older people being more adherent to drug regimens than younger individuals.)

Still, some older patients do not restore their CD4 counts to as high a level as younger patients, and this may be due to the aging process itself. And the decline in the immune system found in all aging adults means that older adults are at greater risk when a failure to diagnose HIV results in delayed treatment.

Older adults' immune systems are further burdened by oxidative stress, or the cumulative damage done to immune cells by molecules called free radicals. HIV further heightens this stress because it uses free radicals to replicate. So antioxidants like beta carotene and vitamins A, C, and E are important for older adults with HIV, and it's best if they come from fruits and vegetables.

Did You Know?

When an older person is infected with HIV, the CD4 cell loss can be greater than in younger people. Studies have found that older people with HIV who are not taking HIV meds are twice as likely to die as younger people with HIV.

Heart and Blood Vessels

Blood vessels lose elasticity and thicken with age. This change places older adults at risk for high blood pressure, heart disease, and stroke. But aging alone does not cause heart disease. There is much that can be done to prevent it – and prevention is a particularly important goal for those aging with HIV, as some anti-HIV drugs may heighten risk for heart disease.

High blood pressure, or hypertension, affects over 60% of people aged 60 or above. It increases the risk of heart attacks, strokes, and heart and kidney failure. When people are successful in lowering their blood pressure to normal, the risk of developing any of these complications is also lowered.

There is no clear link between HIV and high blood pressure. While several studies have shown that blood pressure may rise in people with HIV, this is usually due to aging, smoking, weight gain, or other non-HIV problems. People taking HIV meds do have a higher risk of developing high blood pressure, but this may be due to the changes in cholesterol and triglycerides that can be caused by certain HIV drugs.

Many doctors believe people whose blood pressure is above 135/85 need to be treated. But people with high blood pressure usually have no symptoms for years before they begin to develop complications, so it's important to monitor blood pressure regularly, either at visits to the doctor, at senior centers, or at other health events that target older adults. It's also useful to check blood pressure at home with a digital blood pressure monitor, to avoid falsely high readings that may happen in the doctor's office because of nervousness. The accuracy of a home monitor should be checked by taking it to the doctor's office and comparing its readings to those of the doctor's equipment.

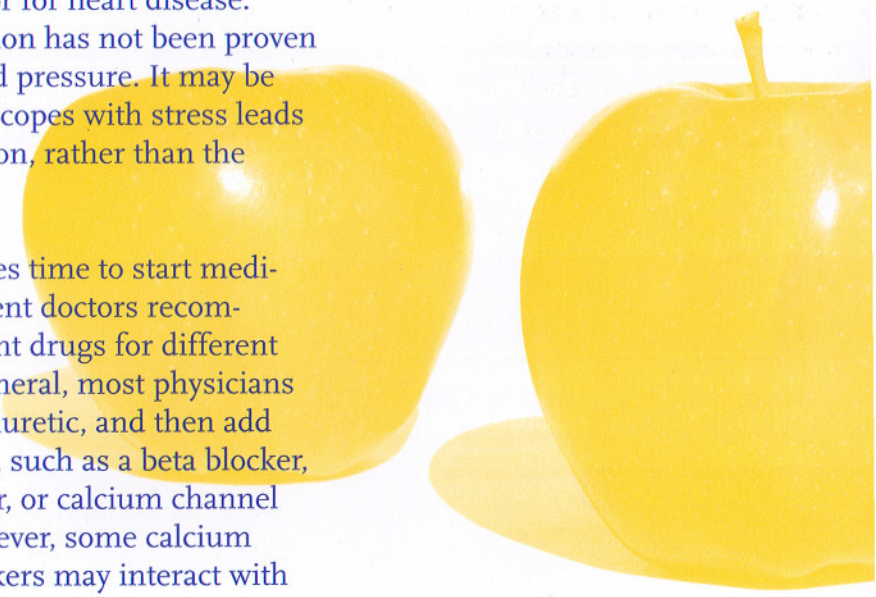
What Can You Do About It?

Blood pressure can be lowered in two ways: by living a more healthy life or by taking medication. Losing excess weight, stopping smoking, drinking less alcohol, using less salt, and increasing potassium and exercise can often be enough to treat mild hypertension. There are many medications available for those whose blood pressure does not respond to these efforts. Frequently, both a healthier way of life and medication are needed.

Even a weight loss of several pounds may be enough to end the need for drugs or to lower the dose needed. Exercise also helps, and moderate exercise is as effective as intense exercise. A 20-30 minute daily walk may be all that is needed. Eating more fruits and vegetables can also lower blood pressure, due to the potassium they contain. Using less salt may reduce the need for hypertension drugs, with or without weight reduction.

Drinking less alcohol (no more than 8 ounces of wine a day, for example) can reduce hypertension and may even help prevent it. Stopping smoking may not affect blood pressure, but it does remove another important risk factor for heart disease. Stress reduction has not been proven to lower blood pressure. It may be that how one copes with stress leads to hypertension, rather than the stress itself.

When it comes time to start medication, different doctors recommend different drugs for different people. In general, most physicians start with a diuretic, and then add another drug, such as a beta blocker, ACE inhibitor, or calcium channel blocker. However, some calcium channel blockers may interact with certain HIV medications.



National Cholesterol Education Program Guidelines

Total Cholesterol

Less than 200	Best
200 to 239	Borderline
240 and above	High

HDL

60 and above	Best (lower risk)
40 to 59	The higher, the better
Less than 40	Low (higher risk)

LDL

Less than 100	Best for people with heart disease or diabetes
100 to 129	Good
130 to 159	Borderline
160 to 189	High
190 and above	Very High

Triglycerides

Less than 150	Normal
150 to 199	Borderline
200-499	High
500 and above	Very High

High Cholesterol & Triglycerides

People who are at risk for heart disease because of high cholesterol will clearly benefit from lowering it. Since most people with HIV over 50 have one or more risk factors for heart disease, they are prime candidates for changing their habits and lowering their cholesterol. In addition, certain HIV meds can raise cholesterol and triglycerides.

There are two types of cholesterol: the "healthy" cholesterol HDL, or high-density lipoprotein, and the "lousy" cholesterol LDL, or low-density lipoprotein.

HDL helps remove cholesterol from the body, while LDL deposits it on the walls of blood vessels, which can lead to heart disease and strokes. Total cholesterol is basically the sum of HDL and LDL.

For many years, doctors considered an LDL level of 100 best, but many doctors now recommend getting it below 100 for people with heart disease or diabetes. The table at left shows the current recommendations for cholesterol levels.

Men over age 45 and women over 55 are at greater risk for heart disease. It's important to know if there is a family history of heart disease, as this increases a person's risk and might lead to earlier use of certain tests and treatments.

Telling It Straight:

I Got More than HIV on My Mind

I continue to take meds for HIV, but other problems manifest themselves as I age – like hypertension, high cholesterol, and depression (which was the hardest thing to deal with). Conversations with my doctor are now only partly related to HIV – they're more about checking my prostate and getting the colon cancer tests that are recommended for men over 50. Thankfully, on those fronts, so far, so good.

Paul Muller, 52

What Can You Do About It?

While people can't change their age or ancestors, there is a lot that can be done to lower the risk of heart disease. Foods that are high in salt can increase blood pressure. Limiting alcohol to only one or two glasses of red wine a day is best (if there are no other problems like gastrointestinal bleeding or certain other illnesses). Increasing the amount of omega-3 fatty acids (found in flaxseed oil, certain fish, and walnuts) can also help, as can reducing the amount of saturated fat.

Exercise may help prevent heart disease. Thirty minutes a day, five days a week is usually enough, but any amount is better than none. Begin by walking at least 20 minutes a day and slowly increasing the time. Good shoes and a safe place to walk are important.

Drugs known as statins are very effective in lowering LDL, but unfortunately many of them interact with HIV drugs. Your doctor will pick those with the least chance of interactions. Other drugs are used to lower triglycerides (another fat in the blood) and raise HDL. But a recent study of health records in California found that people with HIV taking drugs to lower cholesterol were less likely to reach the goals in the table on page 20 than people without HIV. This could be due to the fact that they had fewer drug choices because of interactions between these drugs and HIV drugs.

Did You Know?

Medication is often needed to reduce blood pressure or lower cholesterol and triglycerides. But some meds complicate HIV treatment, and some HIV meds may heighten heart disease risk. Plus, who needs more drugs? Lifestyle changes can help.

- **Exercise.** Walking 20-30 minutes a day may be all that's needed.
- **Lose weight.** Even the loss of several pounds can reduce drug dosages.
- **Eat your veggies.** In one study, people had normal blood pressure after only eight weeks of increasing fruits and vegetables and lowering fatty foods.

Body Weight

Just about everybody thinks they're either too fat or too skinny. But managing aging and HIV means you've got to keep an eye on both possibilities – it's important to avoid being overweight, but as you age it's also crucial to eat enough to maintain the nutrients your body needs.

People lose muscle mass and gain fat as they age, especially if they don't exercise. As a result, the body will burn fewer calories. Diet and exercise can help with these changes, and slow down or reverse the loss of muscle.

Recent studies have found some surprising results: it seems that the thinner a person is (all other things being equal), the longer she or he will live. Certainly, being overweight makes the heart work harder. Losing weight, however, is easier said than done. New research has shown that each person has a weight range that is very difficult to change. That is, someone who weighs 250 pounds may find it very difficult to get down to 150 and stay there. For the extremely obese, surgery may be needed. For the rest of us, the goal is to use diet and exercise to stay at the low end of each body's natural range.

Telling It Straight:

I know that HIV is something that I will have to live with from now on, but as I grow older, I'm also experiencing other health issues. Four months ago, my doctor told me I had high blood pressure. Even though it runs in my family, it was a bit overwhelming to try to deal with this new diagnosis. I wake up every morning and put my feet on the floor even if I feel a little dizzy. I can still see, walk, talk, and think. So with all this being said, I enthusiastically look forward to another milestone in my life and many more wonderful years in my life's journey.

Joan Warner, 64

Diabetes

The body's inability to control blood sugar properly, known as diabetes, is an increasing problem in the U.S., including among people with HIV. The risk for diabetes increases the more a person weighs. It also increases when taking certain HIV drugs, especially protease inhibitors. Type 2 diabetes, the kind that usually affects adults, is tied to body weight, age, and family history – if your parents had it, you are more likely to develop it as well. African-Americans are particularly plagued by diabetes. They are more likely to get it and more likely to die from it once they have it.

Diabetes is managed by losing weight, by changing the diet, and sometimes by taking pills or insulin injections. Often, losing weight is enough to normalize a person's blood sugar.

Diabetes can lead to heart disease and stroke, kidney damage, and damage to the retina of the eye. Diabetic neuropathy, or nerve damage, can also occur and is often difficult to separate from HIV neuropathy, which can be caused by certain HIV meds or by the virus itself. Damage to blood vessels because of diabetes can lead to amputation of the lower limbs because of gangrene, and this risk is greatly increased in those who smoke. But with treatment, diabetes can be controlled and these risks may be lessened.

While gaining weight is a concern for people in their 40s and 50s, maintaining weight can be a concern for some seniors, to sustain energy and the body's ability to repair itself. When a person lives beyond his or her 70s, the ability to digest and absorb nutrients can change significantly, making it difficult to maintain weight. Constipation also can affect older adults, since the intestines may slow down, as do stomach secretions and even swallowing.

The Senses

Vision, hearing, taste, smell, and touch all decline as we age. Again, this is different for everyone. In general, we lose our ability to hear higher pitched sounds, which can make it harder to hear conversations, especially in noisy rooms. The perception of certain types of pain can be decreased with age as well, and it may be harder to identify some flavors and odors. Certain meds, including HIV meds, can cause a change in taste.

After age 40, the need for reading glasses can occur either gradually or almost overnight. Eyes dry out as we age and are less responsive to light, especially in low light. Eye problems such as cataracts, glaucoma, and vision loss due to macular degeneration must be monitored and can often be effectively treated. Fortunately, HIV-related eye infections, such as CMV retinitis, are now uncommon.

Did You Know?

The risk for diabetes increases when taking certain HIV drugs, especially protease inhibitors. And African-Americans, who already are overrepresented in the HIV epidemic, are also particularly hard hit by diabetes. But there's a simple way to fend off adult-onset diabetes, or to lesson the damage it does once you have it: lose weight and exercise.

Dry mouth is probably the most common dental problem seen in people with HIV – it can be caused by HIV meds or other drugs. Low saliva increases the risk of cavities, which can lead to abscessed teeth, so regular checkups are essential for everyone, especially those with dry mouth.

In general, teeth are tough, so it is gum disease that causes the greatest tooth loss in older adults. Regular dental checkups and good oral hygiene can prevent this. Also, the taste buds can change and become less responsive with age. This affects the desire to eat, which can lead to unwanted weight loss.

Nervous System & Mental Health

The changes that occur in our brains mostly affect how the mind processes and uses information and remembers things. The risk for Alzheimer's disease increases with age, but it is not an automatic part of the aging process and is not the only condition that affects mental functioning.

Changes in brain function can make it more difficult to do more than one thing at a time (multi-tasking). It can be more difficult to remember names and numbers. Seniors may find themselves taking more time searching for the right word to use or to recall information. But regular physical activity and mental stimulation may help preserve brain function.

Nerve damage to the hands and feet (peripheral neuropathy), leading to pain or numbness, was common before HIV combination therapy became available. With better HIV treatments, it is seen less often, but diabetes or other illnesses of aging can cause similar symptoms. Pain medications and other treatments may be helpful.

Depressive symptoms are often reported by older adults, both HIV positive and negative. They may interfere with adherence to treatment, doctor visits, social activities, and personal relationships.

It can be difficult for doctors to diagnose depression because many of its symptoms are similar to common HIV symptoms like fatigue, poor appetite, weight loss, loss of sex drive, and sleep difficulties. Also, certain medications (particularly hepatitis C meds) can lead to depressive symptoms. Older adults with HIV and their care providers should pay attention to these symptoms, especially if they occur with other warning signs of depression like mood swings, having the "blues," feeling so sad nothing can cheer you up, or increased forgetfulness.

Many people with depression are treated by their primary providers, not psychiatrists, and increasing numbers of HIV providers prescribe antidepressants. But people with more serious problems, such as bipolar or anxiety disorders or severe depression, should be referred to a psychiatrist. Or, if antidepressants haven't helped within a couple of months, a psychiatric referral may be needed. People taking these meds should never stop them "cold turkey," but rather lower the dose gradually with a care provider's guidance.

Did You Know?

Older people with HIV may be more likely to have symptoms of depression than younger people with HIV, and are more likely to be depressed than people their own age who are HIV negative.

- It's estimated that 5% to 20% of people with HIV suffer from major depression – symptoms that don't go away over time and interfere with daily life.
- Many other people with HIV do not meet the criteria for a clinical diagnosis, but may have several symptoms of depression that can have a negative impact on their lives.

Liver

The liver can actually replace its damaged cells, which minimizes the effects of aging on this essential organ. The most common causes of liver damage are the chronic abuse of alcohol or acetaminophen (Tylenol), especially when taken together.

Although HIV may be present in liver cells, most damage is from co-infection with a hepatitis virus, especially hepatitis C. HIV meds can also lead to liver problems, and switching HIV meds may be necessary in some cases. Certain HIV meds also fight hepatitis B, and could lead to a hep B flare-up if the HIV meds are stopped by people who have both viruses.

People with HIV and hepatitis will do best to lower their use of alcohol and recreational drugs or to stop them altogether. There are treatments available for hepatitis, and it's essential that those who are not infected get vaccinated to prevent hepatitis A and B. Many people with hepatitis find it worthwhile to see a liver specialist in addition to their HIV care provider.

Kidneys

The kidneys (along with the liver) remove toxins from the body, and usually operate quite well even at older ages. Most kidney problems are due to other conditions like high blood pressure, diabetes, or urinary tract infections. HIV has been associated with a specific type of kidney disease known as HIV-associated nephropathy. Although uncommon, it may occur more frequently in African-Americans.

The right HIV meds can improve kidney function in some people, but certain drugs, like Viread, should be avoided in people with serious kidney problems. One HIV med (Crixivan) can lead to kidney stones, so it should be taken with at least eight glasses of water a day.

Skin

The majority of changes in the skin – lesions, age spots, and wrinkles – are due to sun-related skin damage, but the aging process adds to the stress on skin. Aging makes the skin less able to retain moisture and to control body temperature. And skin, along with hair, gets thinner and is more easily damaged.

Reduced production of oils can also lead to dry skin and wrinkles. Sweat helps regulate body temperature by helping the body stay cool. The aging body can be less able to regulate its temperature in response to outside temperature extremes because of a decreased ability to sweat. Certain medications can make the skin more sensitive to the sun, and some HIV meds can cause temporary or more serious rashes, or changes in the skin, nails and hair.

Skin cancer comes in two forms: melanoma and non-melanoma. Non-melanoma skin cancer, such as basal cell carcinoma, is common and very curable. Melanoma is rarer and much more serious. Most skin cancers are caused by overexposure to ultraviolet light from the sun. Using a sun block with an SPF of at least 15 can reduce the risk of skin cancer.

Early diagnosis is important in curing skin cancer, so people should tell their doctors if they notice any change in the size or appearance of a mole.

Did You Know?

Melanoma and another skin cancer, called squamous cell carcinoma, are seen more often in people with HIV and can progress more rapidly. We don't know if this is more serious in older adults with HIV, but given the fact that these cancers are more common in older people, it's likely that people with HIV will be at greater risk for these cancers as they age.

Breast Cancer

Breast cancer is the second most common cancer in women (skin cancer is the most common), but also occurs, rarely, in men. A recent study of more than 85,000 women with HIV in the U.S. found less breast cancer than in HIV-negative women, but the rate seems to be rising.

Most breast tumors are benign, meaning they are not cancerous. Usually a biopsy of the tumor is needed to see if it is benign or malignant (cancerous). If the breast cancer has not yet spread to other parts of the body (like the lymph nodes) it is almost always treatable. But once it has spread, it is harder to control. The good news is that the rate of death from breast cancer has declined over the last few years, probably because of increased screening.

All women should have yearly mammograms after the age of 40, but MRIs give more accurate results in women who are at high risk. People are at higher risk for beast cancer if they have already had it in one breast or have a family history of the disease. Genetic tests are available for those with a strong family history.

Women under 40 who are at high risk need to be followed closely by a doctor skilled in this disease.

Colorectal Cancer

Cancer of the colon and rectum is more common in people over 50 – the rate rises from 15 cases per 100,000 people in their 40s to 400 cases per 100,000 people over age 80. Because colon and rectal cancers have much in common, they are often referred to together as colorectal cancer.

There is no clear evidence that these cancers are more common in people with HIV, but as the HIV-positive population ages, this may change.

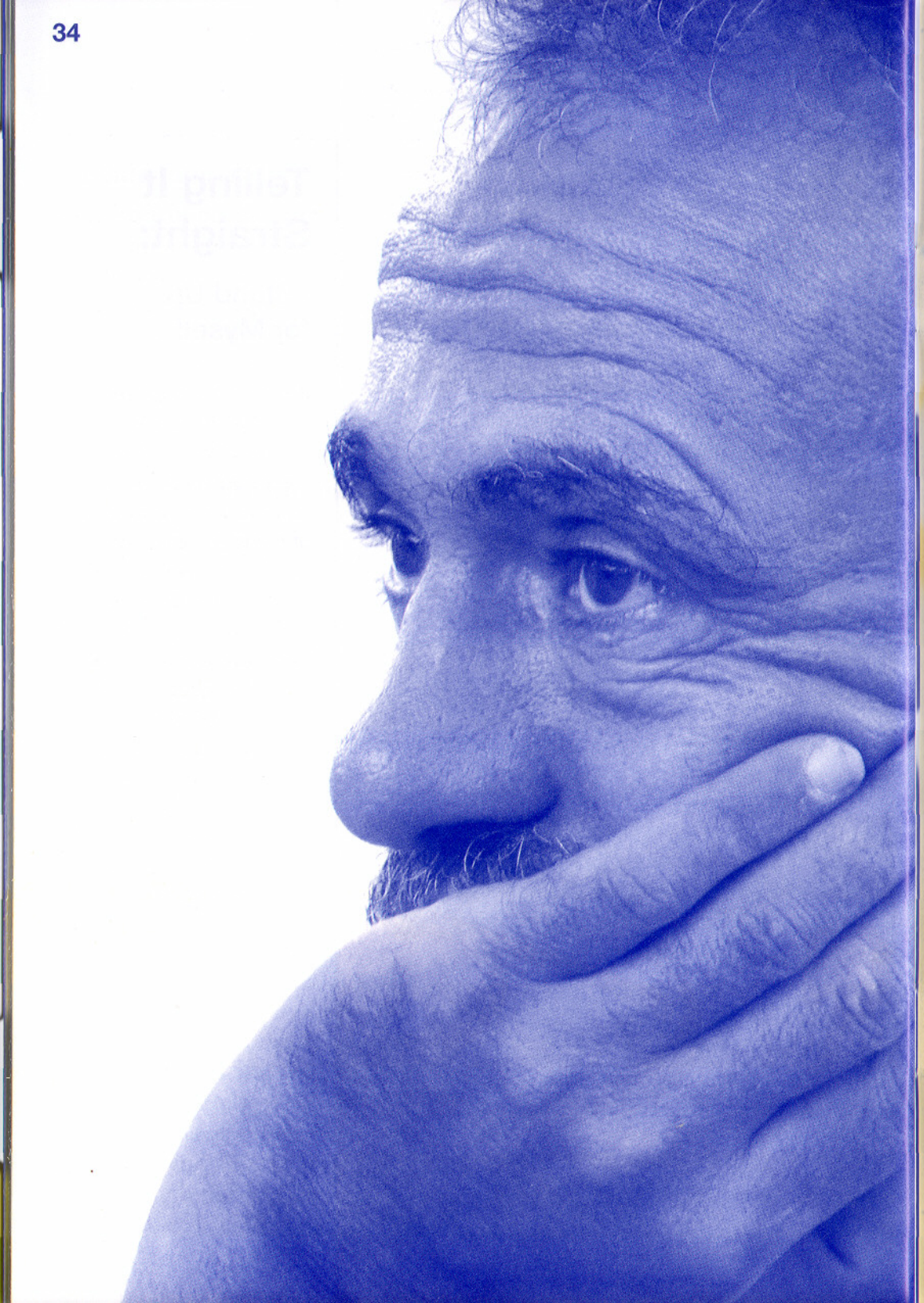
Warning signs of colorectal cancer include blood in the stool, a change in the shape of the stool, or pain in the lower abdomen. Everyone who is over 50 should have regular screenings. Colonoscopies are one option, and are usually done in the hospital on an outpatient basis. A flexible tube, called a colonoscope, with a light at the end is passed through the anus into the colon and the entire length of the colon is examined. The doctor is looking for small growths, called polyps, which can become cancerous. Removing them before this happens can prevent the disease.

Anal pap smears are recommended yearly for certain people with HIV, including men who have sex with men, anyone with a history of anal warts, and women with abnormal cervical tests. HPV (human papillomavirus) can progress faster in people with HIV, so catching it before it becomes cancerous is important.

Endometrial, Cervical and Ovarian cancer

Endometrial cancer occurs in a woman's uterus and happens most often after menopause. The most common symptoms are irregular periods or vaginal bleeding – women with these symptoms should see their gynecologist.

Women with HIV should have pap smears more frequently – some need them at least every six months – because of an increased risk for cervical cancer, especially if they have low CD4 counts. These tests look for changes in cells in the cervix (the part of the uterus that extends downward into the vagina). A large study showed a lower risk of uterine cancer in women with HIV, but a higher risk of cervical cancers, and no increased risk for ovarian cancers. However, cancers of the ovaries are hard to detect at early stages.



Managing Your Meds

HIV meds are definitely easier to take these days: fewer pills, fewer food restrictions, and once-daily dosing of many HIV meds. But they still differ in important ways from other meds older adults may be used to taking. Unlike blood pressure or cholesterol meds, for instance, missing even a few doses of HIV drugs can lead to resistance and treatment failure. So if older adults are to benefit from HIV treatment, special care must be given to adherence education and assistance.

It's Your Life to Control

Much of this booklet has focused on the challenges that all older adults face as they age. It is not clear whether this process and age-related illnesses will be different for those living with HIV. Will the virus and HIV meds make age-related disorders worse? We simply do not know. But people with HIV need to alert their healthcare providers to any new symptoms they have, and to get regular tests for age-related illnesses.

Conversely, living with HIV may help in managing aging. Seniors often need to develop positive coping skills as they age. Could the coping skills that people develop when they live with HIV be useful as they confront the challenges of aging? They may be less threatened by illness and disability. They may be able to accept age-related conditions better compared with those who have not lived with a life-threatening chronic illness.

On the other side of the coin, like people living with HIV, many seniors have developed positive coping skills along with the emotional maturity they gain with age. But life experience is no sure defense against illnesses like Alzheimer's disease, addiction, anxiety disorders, and depression. And aging well is not only about medical care – a healthy social environment and emotional life are equally critical.

Many HIV-positive older adults have been able to find happiness and strength while coping with a challenging illness. They have had the support of a unique system of medical care. Adapting the medical system that has provided this care and support is the challenge facing us as the number of older adults with HIV increases. In the end, it is a challenge that people living with HIV and those who care for them must confront and overcome.

ACRIA

ACRIA is an independent, not-for-profit community-based AIDS research and education organization committed to improving the length and quality of life for people with HIV through medical research and health literacy.

ACRIA conducts an HIV Health Literacy Program to offer people with HIV and their care providers the tools and information they need to make informed treatment decisions. Health Literacy Program services include: workshops conducted at community-based groups throughout the New York City area in English and Spanish; technical assistance trainings for staff of AIDS service organizations; individual treatment counseling; and publications, including a quarterly treatment periodical and booklets in English and Spanish on treatment-related topics. TrialSearch is our online, searchable database of HIV clinical trials enrolling throughout the United States. ACRIA's National Training and Technical Assistance Program offers training and ongoing support to help non-medical service providers and community members in various parts of the country acquire the skills and information needed to provide HIV treatment education in their communities. The Older Adults Training and Technical Assistance Program offers similar services locally and nationally with a focus on the needs of middle-aged and older adults.

To learn more about ACRIA's research studies or the HIV Health Literacy Program, please call or email us at treatmented@acria.org. Information about our programs and copies of all of our publications are also available on our website.

Funding for this booklet was provided by a grant from the M·A·C AIDS Fund and, in part, by the New York City Department of Health and Mental Hygiene.

Free distribution of this booklet was made possible in part by generous donations from U.S. government employees to ACRIA through the Combined Federal Campaign (CFC). CFC #11357

AIDS Community Research Initiative of America
230 West 38th Street, 17th Floor, New York, NY 10018
212-924-3934 Fax: 212-924-3936

www.acria.org

Daniel Tietz, Executive Director

hiv and older adults

ACRIA