POSITIVELY AWARE

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SUMMER 2016

LOVE AND SEX AFTER 60

HELL IN A HOT FLASH?

BLACK GAY ACTIVISTS FROM 2 GENERATIONS

TRANS* FORMING LIVES

OUR GOLDEN YEARS

POSITIVE, OLDER, AND HEALTHY

SPECIAL ISSUE VOLUME 28 NUMBER 4

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ON THE COVER AND THIS PAGE
BACK ROW: JOSEPH MANASSE, BAVINA MOORE, JIM AMBRUS. FRONT: RAE LEWIS-THORNTON, GABRIEL BERNAL, MICHAEL PAYNE, AND GEORGE GARCIA. PHOTOGRAPHED BY JOHN GRESS AT THE TOWN HALL APARTMENTS, AN LGBT SENIOR HOUSING FACILITY OPERATED BY CENTER ON HALSTED, IN CHICAGO.

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POSITIVELY AWARE

JOURNALISM. INTEGRITY. HOPE.

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FROM THE GUEST EDITORS

OLIVIA G. FORD AND MARK S. KING

Telling the story of Our Golden Years

SINCE THE AIDS CRISIS BEGAN in the early 1980s, one group of people swept up in the calamity has most captured our attention and deep empathy: those who were in their 20s during the dawn of the epidemic, whose lives were upended or cut short by the emerging plague.

Through the years, we have watched them face tragedy, minister to the sick and dying, organize a response, and eventually rebound with new medications. It has been a heartbreaking and captivating journey to witness.

As this group now enters middle age and comes under the Centers for Disease Control and Prevention's "older adult" umbrella of 50 and older, the media has responded with a proliferation of stories on HIV and aging that typically focus on *preparing to age*—rather than on those who are already experiencing it.

As guest editors of this special issue of POSITIVELY AWARE, one of us is a survivor and chronicler of the "AIDS generation." The other, as a queer black woman who came of age in the '90s, approaches HIV from multiple intersecting communities. We have both spent most of our adult lives immersed in narratives of the epidemic—often working together, and always learning from one another.

We believe that the story of aging and HIV must include people who were in their 30s and beyond when the epidemic began, as well as those diagnosed when they were already over 50 (who now account for roughly 1 in 6 new HIV cases). Those who have surpassed retirement age have been largely absent from the conversation and media coverage of HIV/AIDS.

The more we considered this, the more we became committed to sharing the stories and lived experience of elder people with HIV for this issue, "Our Golden Years."

A recurring theme in this issue has been a sense of wonder, balanced with consternation, for having lived to experience life stages like menopause; negotiating love and sex after 60; making plans for the end of a life that may well span many more years; or mentoring youth, whether beside a sun-dappled pool or in the thick of building an intersectional movement.

You may also notice, as we did, that issues surrounding aging itself often outweigh HIV in the lives of those we spotlight on these pages. So, too, may HIV be a low priority for people facing high levels of violence, poverty, or discrimination that do not stop as the years accrue. We have also attempted to share narratives and conversations that cross the porous boundaries that often separate people living with HIV by race, age, gender, and HIV experience.

We have been privileged to bring this project to light, with the guidance of the superb staff of POSITIVELY AWARE, and by drawing upon some of the most insightful writers and advocates working in HIV today.

So many cultures throughout human civilization have bestowed great honor and value upon their most senior members. We believe it is inherent upon us all, as people who care deeply about a health crisis that impacts us socially as much as medically, to do the same.

Welcome to our golden years.

Olivia Mark

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ALL SYSTEMS GO

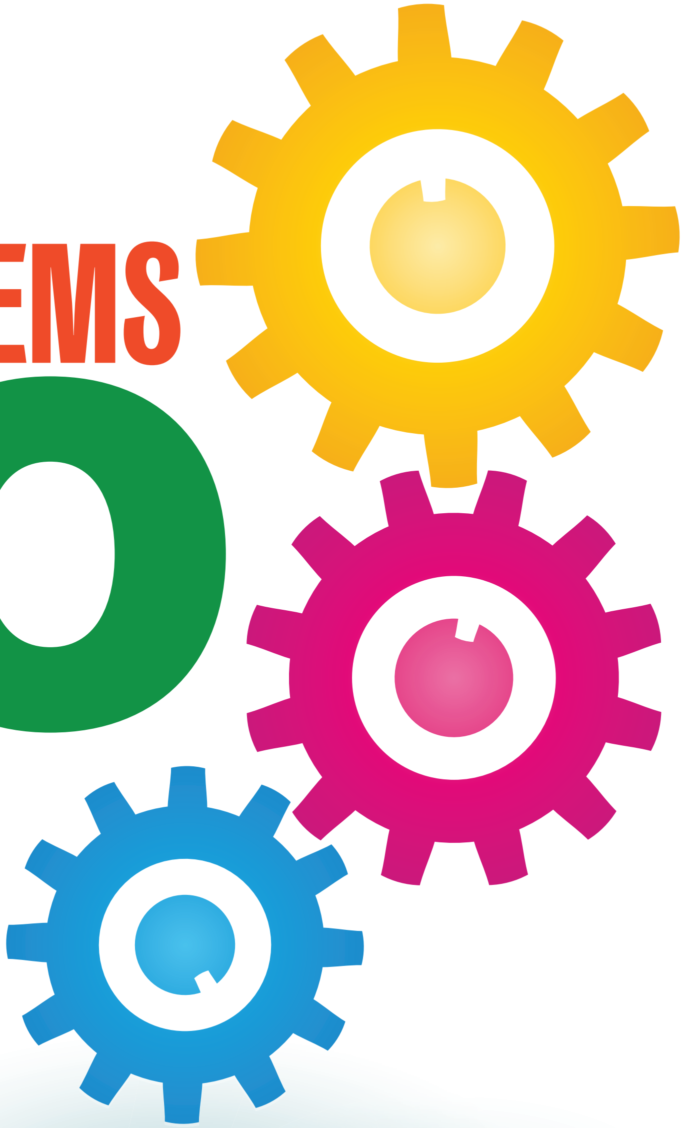


PHOTO: ISTOCKPHOTO

THREE ORGAN SYSTEMS AFFECTED BY AGING, MEDICATIONS, AND HIV

BY SHARON LEE, MD

Aging is an unavoidable characteristic of living. As we get older, our bodies change. Outwardly, our skin develops wrinkles, our hair grays, and inside we change as well. Organ systems become less efficient. Although the American Association of Retired Persons (AARP) defines a "senior" as anyone over the age of 55, more significant physiologic and functional changes show up for most people in their seventh decade and beyond.

HIV disease also causes destruction of cells and organs in our bodies. Some changes are slowed or reversed with medicines that help control the virus, and some may be accelerated by these medications. Although uncontrolled HIV shortens life, several studies in Europe and North America have shown the narrowing difference between life expectancies for people with well-controlled HIV infection and those without HIV.

The question most often asked by gray-haired people with HIV when a symptom or change is noted: "Is this due to aging, HIV, or the meds I take?" However, the more important question is: "What can be done to limit these changes?" Aging cannot be stopped, and the medicines to control HIV are life-saving. But we can choose medicines that have less impact; we can change behaviors to reduce the risks of HIV and of aging-related impacts.

Understanding the intersections of damage caused by HIV, medication effects, and aging on body functions is increasingly important as more people survive longer with HIV. This is an abbreviated look at diseases in three organ systems with an overlap between aging and HIV that are most commonly of concern to my patients.

HEART DISEASE

HEART DISEASE INCLUDES a number of illnesses. HIV causes damage to the heart muscle, as well as inflammation that can reduce the heart's effectiveness in pumping blood by causing cardiomyopathy (weakening of the heart muscle), endocarditis (inflammation of the heart's inner lining), or pericarditis (irritation of the membrane that encloses the heart).

However, the leading cause of heart-associated death among people with HIV is cardiovascular, specifically coronary artery disease. That is disease of the blood vessels that feed the heart. Coronary artery disease is affected by a number of factors. A heart attack happens when the blood vessels (arteries) to the heart itself are clogged enough to prevent blood from flowing to the heart muscle. The muscle cells die without the oxygen carried in the blood. The death of heart muscle is a myocardial infarction (MI), or heart attack.

Atherosclerosis or "hardening of the arteries" increases over our lifespan at different rates depending on our genetic make-up and our lifestyle choices. For example, people who eat diets with higher levels of animal fats, who do not exercise, who become obese, and who smoke are at higher risk of heart attacks at all ages. HIV is associated with increased formation of atherosclerosis. A number of studies show premature atherosclerosis levels in people with HIV compared to age- and risk-matched HIV-negative individuals. These changes are known to be accelerated by the chronic high level of inflammation associated with HIV (at a lower level in even well-controlled HIV disease), and may be exacerbated by some antiretroviral medicines.

Critical to avoiding heart disease is to reduce the inflammation associated with HIV by using ART (antiretroviral therapy). The suppression of HIV is associated with lessening of inflammation. Controlling the viral levels has been shown to lower risk of cardiac death. Studies have shown up to a 70% decreased hazard for cardiac events for people with HIV who start ART medicines sooner rather than later.

Some of the medications used to treat HIV are associated with increasing levels of cholesterol and/or triglycerides (other fat molecules associated with heart disease), but even those medicines are associated with improvements in heart-related deaths because of the reduction of inflammation that accompanies improved control of the virus. Making smart choices in antiretroviral medicines and avoiding those associated with increases in cholesterol when possible improves heart risks.

The U.S. Department of Health and Human Services' HIV guidelines recommend testing cholesterol and triglycerides (lipids) before and after starting ART. Higher levels may lead a health care provider to avoid Norvir (ritonavir) or other medicines that tend to increase lipids, and possibly to add lipid-lowering medicines to the patient's regimen to decrease cardiac risks.

KIDNEY DISEASE

KIDNEY DISEASE INCREASES with aging, particularly in people with a family history of kidney disease. It is also impacted by HIV and some of the medications used to treat it. Studies have found that people over the age of 80 have more than 30% scarred and inactive renal (kidney) cells compared to people under 40, with only about 1% of cells with this scarring. Renal disease increases over time and is also associated with other diseases that worsen with age, such as diabetes.

HIV damages the kidneys in two ways:

1. HIV is found inside kidney epithelial cells, where it causes death of the cells (HIV-associated nephropathy, or HIVAN). African American men with HIV appear to be at greatest risk of HIVAN.
2. HIV also injures the kidneys through immune complex deposits—molecules that are created by the human body's attempt to fight HIV and that cause inflammation, thus destroying kidney cells.

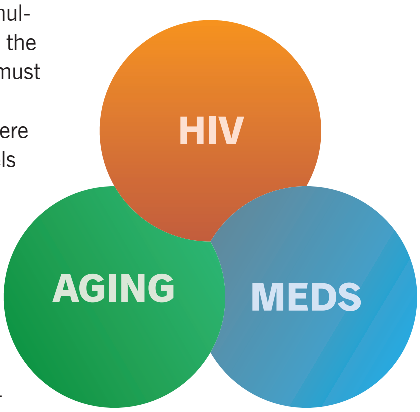
Medications used to treat HIV may have direct toxic effects on the kidneys. Choosing HIV therapy requires balancing multiple factors, and sometimes the risks of a specific medicine must be weighed with the benefit (particularly in situations where a person's HIV has high levels of resistance to ART). It is important to start HIV treatment early (before injury increases), and to carefully choose HIV therapy to best protect kidneys by potentially avoiding Viread (tenofovir DF) or other nephrotoxic medicines, especially if there is a risk of kidney problems that runs in the family. (A new formulation of tenofovir, tenofovir alafenamide or TAF, is associated with less kidney problems; it is available in several new fixed-dose tablets.)

Antiretroviral medications help prevent the kidney injury associated with HIV infection. Studies have shown that early and continuous ART prevents HIV-associated nephropathy. There is also evidence that controlling HIV reduces the immune complex deposits and inflammatory impact on the kidneys.

Some of the kidney injury in HIV infection is also associated with secondary infections such as hepatitis C or syphilis, and to the worsening impact of these infections due to poorly controlled HIV. Avoidance and treatment of these infections can have a protective effect for the kidneys.

CENTRAL NERVOUS SYSTEM DISEASE

CENTRAL NERVOUS SYSTEM (CNS) disease is perhaps the



UNDERSTANDING THE INTERSECTIONS OF DAMAGE CAUSED BY HIV, MEDICATION EFFECTS, AND AGING on body functions is increasingly important as more people survive longer with HIV.

greatest fear for many. HIV and aging similarly affect cognitive abilities, and together appear to increase this effect. AIDS dementia complex (ADC) occurs more often in people with advanced HIV. ADC is most likely to occur in people with CD4+ T-cell counts below 200 cells/mm^3, and has been shown to be about seven times more likely in people with CD4+ levels under 100 cells/mm^3. Multiple studies have shown an increase in ADC is associated with higher viral levels in the CNS.

The CNS has an extra protective barrier (the blood-brain barrier) that prevents many toxins or infectious agents from entering the central nervous system and harming the brain. HIV crosses this barrier by riding inside macrophages—white blood cells with CD4+ receptors on the surface. These cells carry HIV internally as they cross into the brain.

Once inside the brain, HIV has at least three ways it can cause damage:

1. HIV destroys brain cells by infecting neurons (brain cells whose job is to send messages to other cells).

2. HIV causes damage to neurons through infection of other cells in the CNS, called microglial cells (similar to macrophages). These cells have surface CD4+ receptors like macrophages, and therefore allow HIV access.

3. An indirect effect of HIV infection in the CNS is to increase cell-produced inflammatory chemicals (called cytokines and chemokines). A high level of inflammation can become damaging to the neurons.

ADC is an AIDS-related disease in which earlier HIV treatment reduces the likelihood of severe dementia. Since the advent of highly effective antiretroviral therapy, the proportion of people with HIV who develop ADC has dropped from 30–60% to 1–10% among people with HIV on ART. ADC is also known to improve in people who take ART medications regularly.

CONCLUSION

THE HEART, KIDNEYS, AND BRAIN all change as we age, and those changes are generally noted to occur sooner and to a greater degree in people with untreated HIV. Although the medications used to treat HIV are not without side effects that include some negative impacts on aging, they have been found to have a mostly positive effect. In the current era, people with well-controlled HIV can have life expectancies similar to people with similar risk factors who are not living with HIV.

There is still a great deal to learn. We as humans are living through our first life cycle with HIV, and are early in our first cycle with HIV medications that may contribute to problems associated with aging. People living with HIV, and scientists who study the virus, are pioneers extending our knowledge of the effects of HIV and aging.

SHARON LEE, MD, is the founding physician and director of Family Health Care, a non-profit clinic in Kansas City, Kansas, and an associate clinical professor at the University of Kansas.

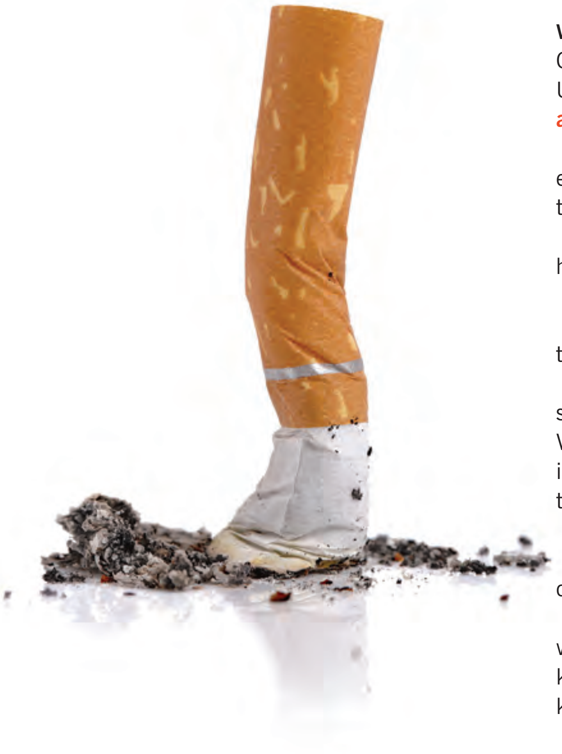


PHOTO: ISTOCKPHTO / BRIAN A. JACKSON

It's never too late to quit smoking

WE ALL KNOW that smoking is a serious health issue. According to the Centers for Disease Control and Prevention (CDC), about 19 percent of U.S. adults smoke—and **the smoking rate is two to three times higher among adults living with HIV**.

The habit of cigarette smoking often follows us into later life, but it can end there, too. Just ask Rev. Andrena Ingram and Bob Leahy, both long-time HIV survivors who put down the pack after years of puffing away.

POSITIVELY AWARE asked them to share their thoughts on quitting the habit—and for one piece of advice for others who want to do the same.

Rev. Ingram is 61 years old and quit smoking nearly three years ago:

"Aside from obvious health benefits, I was tired of smelling like an ashtray. It became an emotional health thing.

"What helped me, besides the patch, were bars of Yardley Lavender soap. Had one on my desk, throughout the house, and in my handbag. When the urge to smoke hit, I pulled the bar of soap out and deeply inhaled, thinking, 'Ahhhh, this smells so much better than a cigarette; this is what I want to smell like.'"

Bob Leahy is 69 years old and dropped his nicotine habit 15 years ago:

"Experts say quitting is the very best thing a person living with HIV can do for their health, and I agree.

"Most people have a history of quitting attempts. In my case there were three or four. But I think I learned from each try so that in the end I knew what didn't work, like having 'just one.' With just that one piece of knowledge, and a tiny bit of will power, it was surprisingly easy."

—**OLIVIA G. FORD AND MARK S. KING**

NOT SO FAST

DO PEOPLE WITH HIV REALLY EXPERIENCE ACCELERATED AGING?

BY DAVID ALAIN WOHL, MD

PHOTO: ISTOCKPHOTO

RECENT TALK ABOUT HIV AND AGING has almost always been scary. A number of studies conclude that people living with HIV have so-called "accelerated aging"—meaning they will suffer heart attacks, strokes, cancers, and osteoporosis more often and sooner than those without HIV. Reading and hearing about these concerns can be disheartening, especially for those who have fought so hard, over so many years, to control their HIV.

Well, this is one article on aging and HIV that will challenge the concept of people living with HIV having an early expiration date. Instead, we can look at what we know and what we don't, to get a better idea of what the risks are for HIV-positive people growing older—and what they can do about them.

FACT: HIV-positive people have higher rates of age-related conditions.

HIV-positive people are definitely at increased risk of cardiovascular disease, certain types of cancers, neurocognitive impairment, and weaker bones (collectively what I will call "age-associated badness"). I know, that is a pretty gloomy realization to start with when trying to argue that HIV infection does not lead to accelerated aging. However, what the statistics show us is that people living with HIV have a greater chance of these serious problems, to a large extent, because they are more likely to have the *traditional risk factors* for each of these conditions—the factors that are seen in the general population as the main drivers of such conditions.

For example: People who smoke, don't exercise, eat unhealthy diets, and live with high levels of stress are more likely to have cardiovascular disease than those without these risks. Rates of smoking alone are up to three times higher among HIV-positive people than in the general population. It is not a stretch to say that people living with HIV are also more likely to experience those other traditional risks. Therefore, it follows that people with HIV would have more heart attacks and strokes—and they do.

The same goes for cancer, cognitive concerns, and brittle bones. Mental illness, substance abuse, and head trauma can lead to cognitive issues, and those are risks that people with HIV more often have. While a number of studies have shown HIV to be associated with low bone density, a recent study of HIV-negative men enrolled in a study of pre-exposure prophylaxis (PrEP) found higher than expected rates of bone density problems in these men *before* they started on the study drug. Alcohol and methamphetamine use were both associated with more brittle bones.

Certainly, researchers try to account for imbalances in risk when comparing HIV-positive and HIV-negative people. The problem is that it is hard to account for all of the most potentially influential factors, let alone those that are less obvious. Depression, poverty, discrimination, and certain types of substance use have been linked to poor health outcomes, but are hard to measure and are not typically included in

OLDER HIV-POSITIVE PEOPLE MUST TAKE GOOD CARE OF THEMSELVES, PHYSICALLY AND MENTALLY. This means eating healthily, exercising, managing problems such as obesity, diabetes, and high blood pressure, getting all recommended vaccinations, and using care to avoid sexually transmitted infections.

PHOTO: ISTOCK/ KALI NINE

these adjustments. We are left with possibly comparing apples to oranges when comparing HIV-positive and HIV-negative people, and attributing excess risk to the virus or its therapies rather than an unaccounted-for imbalance in other risk factors.

FACT: The risk of age-related badness can be reduced.

In contrast to the notion that the development of age-related badness is a foregone conclusion, people living with HIV often have the power to tilt the odds in their favor by taking action. Not all risks can be eliminated, for sure. You can't take back 30 years of smoking, but you can *stop* smoking. Moreover, you can also reduce your risks in very traditional ways.

Heart disease risk

LIKE ANY AGING AMERICAN, people with HIV should have their risk of cardiovascular disease assessed by their clinician. Using cholesterol values, blood pressure readings, age, race, and diabetes and smoking history, the 10-year and lifetime risk for cardiovascular disease can be easily estimated based on data from huge numbers of people (yes, there is an app for that). This risk score can inform recommended interventions—from doing nothing, to making dietary changes and exercising, to starting medication.

Cardiovascular disease risk can absolutely be reduced, with lifestyle changes, as mentioned; better control of blood pressure and blood sugars; and in many cases medication, particularly drugs like lipid-lowering statins or aspirin. Recent data even show that rates of heart attacks and strokes among HIV-positive people in care have dropped and are now about the same as those for HIV-negative people. This has been attributed to some of the factors I've mentioned, including smoking cessation, control of cholesterol and blood pressure, and the push for an earlier start of HIV medications.

Bone loss risk

FOR BONE HEALTH, a similar calculator can be used to assess the risk of osteoporosis; and action can translate into risk reduction. There are guidelines for when to measure bone density using X-rays called DEXA scans. Older people living with HIV should ask their health care providers about whether they need a DEXA scan or not. When low bone density is identified, it can sometimes be explained by low vitamin D or testosterone levels. Simple supplementation with vitamin D and calcium can help improve bone health; stronger medications can be used for more severe cases.

Cancer risk

ANOTHER WAY that HIV-positive people can help make sure that the force of prevention is with them is to get the recommended routine cancer screenings. Recommendations are pretty clear about screening for cancer of the colon, breast, cervix, lung (for those with significant smoking history), and liver (for those with cirrhosis and hepatitis C or B). Early detection of these cancers can lead to early treatment and, in many cases, cure.

Too often people, with and without HIV, stall on getting potentially lifesaving colonoscopies or mammograms. Not a good idea. These screenings are notorious for causing discomfort, but you have gone through worse. Take a deep breath, and get screened.

A few more ounces of prevention

WE SHOULD NOT short-change other interventions that help people stay healthy as they age. These include basic things, like vaccinations. Many people don't get the influenza vaccine, believing it will make them sick—placing themselves and others, including children, at risk for this potentially devastating infection. The flu shot cannot cause the flu (it is an inactive vaccine—not alive!). We should all get it every year. Other important vaccines include those for strep pneumonia and shingles.

Other no-brainers when it comes to aging well with HIV include good recordkeeping of all medications, even over-the-counter and alternative ones. Bring a list of all your drugs and supplements to the clinic to help your health care providers avoid drug interactions or errors that could be harmful.

Older people also have sex, thank goodness, and no one should age out of asking about and being screened for sexually transmitted infections.

Lastly, depression is highly prevalent among people with HIV, as well as older folks. This needs to be looked for and addressed. Besides medicine, social support can help and is critical to well-being. (Check out the conversation between David Fawcett, PhD, LCSW, and Gina Brown, MSW, about social isolation among older adults living with HIV, later in this issue.)

Five golden diet and exercise tips

POSITIVELY AWARE ASKED 34-year HIV survivor **Nelson Vergel**—author of the seminal book on exercise and nutrition for people with HIV, *Built to Survive*—for helpful advice on staying fit throughout your golden years. Here is Nelson's advice:

Make your breakfast the largest meal, followed by a medium-sized lunch and a small dinner. People who skip breakfast have a higher chance of gaining weight and developing insulin resistance. Eating a large dinner can make you fat, disrupt your sleep, and lower your morning appetite.

Walk a minimum of 30 minutes per day. Walk your dog, ride a bike, park your car away from your destination, or use the stairs. If you have trouble with mobility, there are low-impact exercises that can be done while seated in a chair that stretch your spine and strengthen your core. There are many online videos demonstrating seated workouts, but always be sure you consult your physician first.

Do not go hungry or thirsty. Eat small protein-rich snacks every three hours like nuts, hummus with crackers, cheese with apples or celery, etc. Drink water through the day (if you are thirsty, you are dehydrated!). Proper water consumption and snacks will prevent binge eating later in the day and will keep your blood sugar, insulin, and energy more stable.

If you are tired, talk to your doctor about your sleep (and a potential sleep apnea test). Ask about increasing your hormone levels if they are low, since low testosterone and thyroid can make you gain fat and lose lean muscle mass.

Program your mind. Post a picture of yourself looking fit in the past on your bathroom mirror. Tell yourself every day that you deserve health. Do not overwhelm yourself with too many lifestyle changes at once; that will set you up for failure. One change every week or two is a safe bet.

FACT: Studies show higher levels of markers of inflammation in people living with HIV, and these are associated with age-related badness.

Inflammation is our body's way of responding to damage or threats. Hit your thumb with a hammer and you get lots of inflammation in your thumb. This is because damaged cells sent signals to other cells that something harmful happened and needs to be dealt with. Less obvious is inflammation that occurs in response to more chronic insults like bad gum disease, high-fat diets, or infection with HIV. Here, too, signals are sent and can provoke responses that, unlike the sore thumb, persist, keeping the body in an active state of response that can hurt organs over time.

A number of studies have shown that HIV-positive people *in general* have higher levels of markers (signs) of inflammation than those without HIV. Studies of patients with undetectable viral loads on HIV medications show that levels of inflammation markers are closer to normal but, in general, are still somewhat higher than for those who are HIV-negative.

Note the use of "in general." This is to make loud and clear that these studies do not show that *all* people with HIV have high levels of inflammation. In fact, the studies looking at this have found a range of inflammation among HIV-positive people with many (maybe most) having low levels of inflammation. It is only when they look at overall averages that they can see differences between groups.

Additionally, it is unclear what these levels of inflammation really mean, as they can change over time and we don't know for certain what is a good, concerning, or dangerous level of inflammation markers. It is also hard to know to what extent any of the inflammation seen in these studies is due to HIV, HIV medications, or something that is more unique to HIV-positive people. There may be a role that the virus continues to play, even when controlled, that contributes to age-related badness, but with so much else going on, it is hard to say how big this role is.

Actions that can help reduce inflammation include the usual suspects: good diet, good weight, good exercise, good control of diabetes, good control of blood pressure, and so on. HIV therapy itself (especially started early, before CD4+ cell count declines) reduces levels of inflammation markers—likely by controlling the virus—and that may be the most important intervention of all for HIV-positive people getting older.

Conclusion

PEOPLE LIVING WITH HIV are not powerless against the onslaught of age-related badness, and need to be proactive regarding their health as they get older. Ask your health care providers about assessments of risks for cardiovascular disease and low bone density. Screening for cancers is a must.

On the other side of the stethoscope: Older HIV-positive people must take good care of themselves, physically and mentally. This means eating healthily, exercising, managing problems such as obesity, diabetes, and high blood pressure, getting all recommended vaccinations, and using care to avoid sexually transmitted infections.

For all the handwringing about HIV and aging, we cannot lose sight of the facts: The survival rate for people living with HIV in the U.S. is now incredibly close to that of the general population. That does not mean we know it all, but it means a lot.

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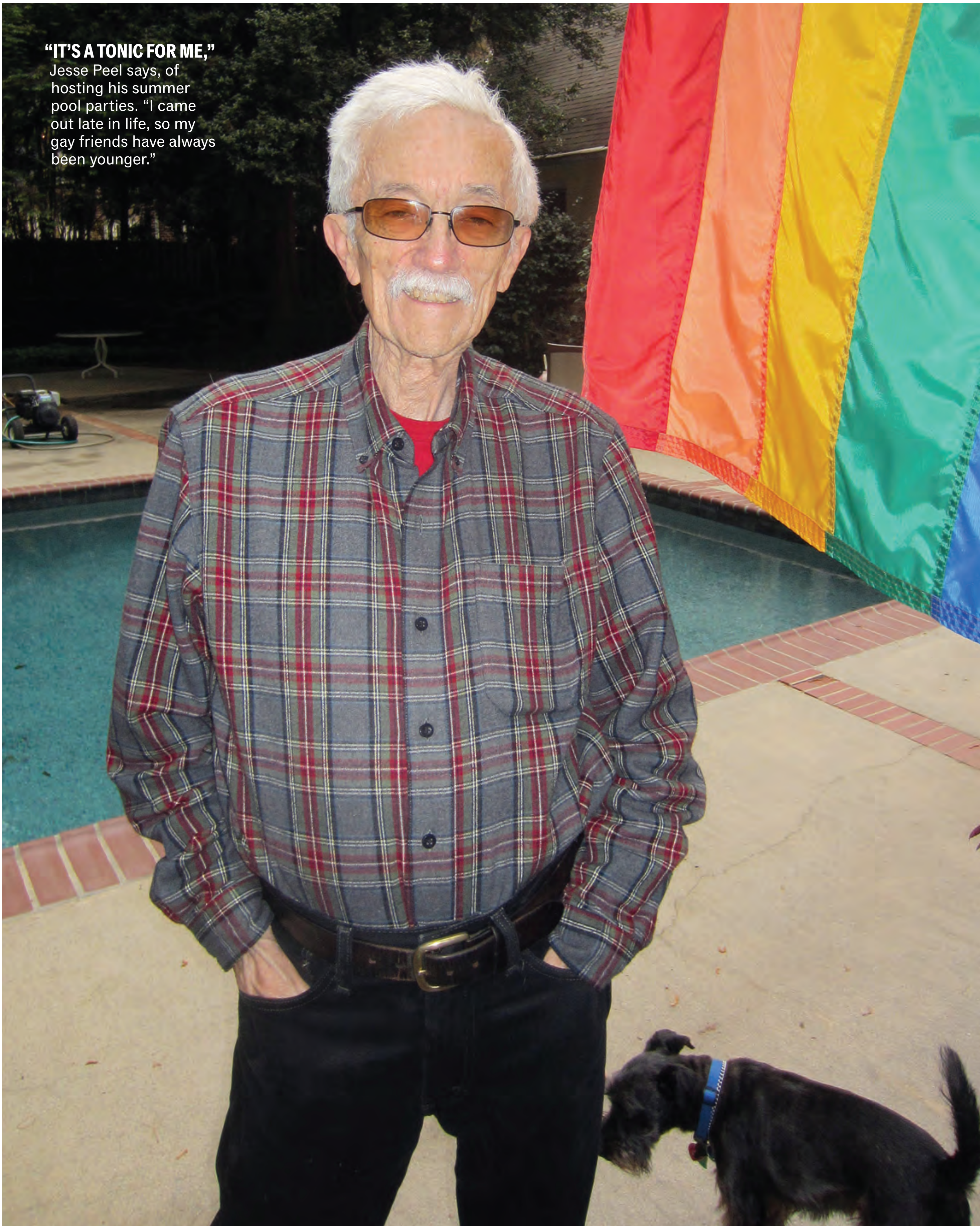


"IT'S A TONIC FOR ME," Jesse Peel says, of hosting his summer pool parties. "I came out late in life, so my gay friends have always been younger."

PHOTO: CHARLES GREEN

JESSE PEEL IS AGING SWIMMINGLY

HOW ONE RETIREE IS STILL MAKING A SPLASH IN HIS 70s

BY MARK S. KING

Jesse Peel credits the pool in the backyard of his Atlanta home for his continued good health. But not because he's swimming laps.

"My pool parties are incredible," said the 76-year-old retiree. On most Sunday afternoons each summer, Jesse welcomes at least 50 gay friends to his lushly landscaped pool, where spirits are high and clothing is optional. But please don't get the wrong idea.

"This is not a sex party," Jesse explained about the gatherings, where he is decades older than most of his guests. "I'm just fortunate that I have built a social network of guys who enjoy the company of an old fart like me."

On a typical balmy Sunday, Jesse can be found holding court under an umbrella by the pool, greeting guests while working on *The New York Times*' crossword puzzle. "It's a tonic for me," he said. "I came out late in life, so my gay friends have always been younger. And people don't think about the benefits of cross-generational friendships. Having vital people in my life means I have someone to call if I need help."

Asking for support comes after a lifetime of supporting others. A psychiatrist by profession, Jesse either founded or had a hand in launching nearly every HIV agency in Atlanta, dating back to serving on the board of AID Atlanta in 1984. Much of his work was done after his own HIV diagnosis in 1987, at age 47.

Although his blood work has remained stable, Jesse has dealt with health concerns as he has aged, such as bowel problems and compromised kidneys due to side effects from long-term medication use.

"It sucks," he said, summing up these concerns—but he doesn't blame them on his virus. To Jesse, HIV is "just one of the pills I take. It's not the focus. I also have medications for cholesterol, my heart, and my prostate."

In fact, Jesse believes the health care he receives for HIV has contributed to his longevity in other ways. "I see my doctor every three or four months for regular labs," he said, "and that enables him to monitor my entire system."

Jesse has always been trim, but since having heart surgery five years ago, keeping weight on has been his biggest challenge—and aging hasn't helped. "Getting the proper nutrition and eating regularly is harder," he said, "especially since I live alone and have to prepare meals for one."

While there has been curiosity and gossip about his friendships with younger men, Jesse is candid about his experiences with sex at 76. "I don't remember how long it's been," he admitted. He keeps a supply of Viagra on hand should the need arise, and he enjoys reading internet porn. "When I read on the computer," he added with his usual good humor, "at least it lets me increase the size of the text so I can see it!"

Despite having been a key figure among HIV organizations for decades ("I knew I had to stay active to survive," he said), his time and philanthropy are now focused elsewhere. "I had given all I had to the AIDS community," he recalled.

Jesse has recently become involved with Lost-n-Found, a new Atlanta agency that assists homeless LGBT youth.

"You can't wait for life to come to you. Take risks," Jesse advised. "Be involved with younger people. Some folks might not be interested, but that's okay." Those relationships can include family. "If you have nieces and nephews, get involved in their lives. We are the keepers of a lot of old family secrets," he added. "Scandalize them!"

Beyond his volunteer work, Jesse keeps busy by seeing local theater and making dinner dates with any one of his large cadre of friends. The dinners in particular help him eat regularly while providing important social support.

When asked what he imagines his life will be like in another 10 years, he didn't shy away from the question. "I hope I'm mobile," he answered. "You never know. I hope I'm still living alone, which I like."

"When I retired in 1992," he continued, "my goal was to be here for the Atlanta Olympics in 1996. Then the new HIV drug cocktail happened, and my goals just kept spreading further out in front of me. I'm hoping to reach 80."

But Jesse has more immediate plans. "Did you know Bette Midler will be on Broadway in 2017?" he asked. "You *know* I've got to see that!"

All about attitude

When Eva Hansen's throat began to swell one day in 1983, she had no idea her life was about to change dramatically. Within days, both she and her husband had received an AIDS diagnosis. Eva would care for him until his death in 1988.

"I thought I would die every moment," Eva said about those early years. "I was 40 years old when I found out, and now I'm 74. They told me I had six months to live. I've had more than 30 years!"

Eva gives much of the credit to a busy schedule of friends, church, and travel, which is her biggest passion. Eva's refrigerator is covered in magnets representing cities she has visited around the globe, and she isn't done adding to them yet. "I'm going to Denmark and Sweden in a couple months with some girlfriends," she said of her traveling support system, all in their 70s. "And in the fall I will go to Dubai."

While her HIV blood work has been stable for years, Eva does worry about other aspects of her health. "I'm definitely afraid of falling," she admitted. "With aging, your knees start to go. You can't stand like you used to. It feels like the bones in your hands stick. And my eyesight is going just a little."

Eva counters her ailments with vitamins and medication for high blood pressure. And she maintains a positive attitude. "You've got to look on the bright side," she said. "I have the freedom to do what I like, and I fill my time helping other people. I've actually had less stress as the years have gone by."

Eva advises others to surround themselves with people who encourage them. "I don't have the patience to be around people who are negative," she said. "I can't just sit around at home and mope. And I have a lot of traveling to do. I still need to cross Malaysia off my list."

— **MARK S. KING**

HELL IN A HOT FLASH?

FACTS AND PERSPECTIVES ON MENOPAUSE AND HIV

BY RAE LEWIS-THORNTON

WHO WOULD HAVE THOUGHT that medical advancements would defy single-digit T-cell counts and the expectation of death, allowing numerous women aging with HIV to experience the challenges of the "change of life"?

AFTER A WEEK of waking up in the middle of the night with drenching night sweats, I ran to my doctor in a panic reminiscent of the days when my T-cell count was 8. I just knew something major was wrong with me, despite my undetectable viral load. Imagine my surprise when my doctor explained that I had entered perimenopause.

Thirty-five years into the pandemic, HIV is no longer a death sentence, and women living with HIV are aging straight into menopause and beyond. However, information about the impact of menopause on positive women is clouded by limited research, with mixed results from the few studies that have been conducted.

Menopause, often known as "the change of life," is the changing of a woman's hormone levels. Basically, a woman produces less estrogen as she grows older, causing a hormonal imbalance and ultimately eliminating a woman's menstrual cycle. Perimenopause is the time of transition from the beginning of hormonal changes to the ending of the menstrual cycle, when a woman is no longer able to have children.

So what's the big deal? No more "periods" is a dream many women have had since their teen years. If only it were that simple. In reality, perimenopause is often a long, daunting process for women.

One desirable aspect that many women experience in this stage is lighter and fewer menstrual cycles. Less attractive symptoms can include:

- HOT FLASHES
- DEPRESSION
- SLEEP DEPRIVATION
- WEIGHT GAIN
- IRRITABILITY
- MOOD CHANGES
- DRENCHING NIGHT SWEATS
- VAGINAL DRYNESS

Of these symptoms, hot flashes tend to be the most intrusive in a woman's daily routine. Women often describe

hot flashes as being akin to spontaneous combustion: a sensation that suddenly emerges from the inside out, leaving you feeling as if the inside of your body has been set on fire. While perimenopausal symptoms, and their severity, vary from woman to woman, a 2014 study in the journal *Menopause* found that women living with HIV have more severe hot flashes than HIV-negative women.

For me, the most disconcerting finding of the study was that the distress of hot flashes could interfere with healthy life choices, and even HIV medication adherence, for women living with HIV. The fact that hot flashes can impact quality of life is no secret to women who have experienced them. La'Donna Boyens of Norristown, Pennsylvania, diagnosed with HIV in 2000, concurs. She explained that her hot flashes are so intense that she no longer wears socks with her boots in the winter, and carries perfume to combat the smell of sweat. "I never want to go to hell," La'Donna said, "if it feels like a hot flash."

Hot flashes while sleeping can be the cause of night sweats—and sleep deprivation. Waking up in the middle of the night with soaked pajamas has become the norm for many perimenopausal women with HIV. For example, my night sweats are so extreme that I now sleep with the heat off in my bedroom—on Chicago winter nights. "Sleeping at night, I feel like a zombie in a sauna," Tiffany Quinton, an AIDS activist living with HIV in Houston, said. The *Menopause* study concluded that irritability and loss of sleep from hot flashes were part of what diminished quality of life for HIV-positive women. La'Donna agrees: "Some days I don't want to leave the house," she said; "That's just not me."

Studies have revealed conflicting results as to whether women with HIV enter perimenopause earlier than HIV-negative women. Women's Interagency HIV Study (WIHS) results presented in 2004 by lead investigator Dr. Helen Cejtin found no significant difference between HIV-positive and HIV-negative women—the mean ages were 47.7 and 48 years, respectively. Another study, published in the *International Journal of STD & AIDS,* concluded that women with HIV who had T-cell counts of 200 or below, had a history of injection drug use, or were of African descent tended to experience earlier menopause. Other factors, including tobacco smoking, have also been linked to earlier menopause in some studies.

A major concern for menopausal women living with HIV is bone loss. We know for sure that both men and women living with HIV are at higher risk for bone disease. Additionally, women lose about 10% of their bone mass during the menopause process. Changing hormone levels are widely believed to be responsible for this thinning of the bone. This combination of menopause and HIV leaves HIV-positive women at higher risk of bone disease.

Dr. Cejtin, the WIHS study investigator—who also happens to be my gynecologist—takes a proactive approach to screening for bone loss. Since HIV already causes bone loss, she recommends a DEXA bone scan for all her patients who have begun the perimenopausal phase, to determine their baseline bone mineral density. Other recommendations for women with HIV to combat bone disease include adequate nutrition, quitting smoking, doing weight-bearing exercises such as lifting weights at least three time a week, and daily calcium and vitamin D supplements.

The more women live longer lives with HIV, the more research can be done on the effects of HIV on the menopause process. In the meantime, women have to take advantage of everything we currently know, to live the healthiest life possible with HIV and menopause. One key step is diagnosing perimenopause. If you are in your mid-40s or older, if your body just seems "off"—sweating, mood swings, loss of concentration, irregular menstrual cycles—you can ask your doctor to test your hormone levels. A hormone test is a start, though symptoms are often the best way for a provider to know if you have entered perimenopause.

Just like every woman's menopause is different, every woman must decide for herself which route to take to treat the symptoms that may come with it. Hormone replacement therapy is an option. Tiffany and I have chosen to take hormone replacement therapy. We both take oral Premarin, an estrogen replacement therapy, every day alongside our antiretroviral medications. I take a higher dose than normal, because one of my HIV medications decreases the effectiveness of the estrogen. I also use Premarin cream to treat vaginal dryness. Although La'Donna has chosen not to take hormone replacement therapy, she and I both take antidepressants to relieve the symptoms of depression and mood swings.

Aside from medical treatments, adding exercise to our daily routine is also important for women aging with HIV. Exercise is a win-win: It aids in maintaining a healthy heart, helps ease depression and mood swings, combats bone loss, and so much more.

The burdens and joys of being a woman have always taken center stage when it comes to HIV. Chronic yeast infections, cervical dysplasia, and irregular menstrual cycles were the norm for women living with HIV in the earlier days, and many of us who survived have managed these issues well. We must do the same as we age with HIV.

Despite the issues surrounding menopause for women living with HIV, the fact that it means we're living longer is certainly music to our ears. Tiffany was diagnosed with HIV in 1995 and remembers clearly the day the health care worker informed her that she was dying. She put it this way: "I would prefer to deal with the symptoms of menopause over death from AIDS."

No matter how you choose to manage your perimenopause symptoms, know that life even with a hot flash is worth living. I'm a living witness, having lived with HIV for 33 years.

RAE LEWIS-THORNTON is an Emmy award-winning activist, life coach, award-winning blogger, social media expert, author, jewelry designer, and tea connoisseur living in Chicago. She lectures worldwide on the topic of living with HIV.

MENOPAUSE: ISTOCKPHOTO RAE LEWIS-THORNTON: JOHN GRESS

CAN OLDER PEOPLE GET SOME... SATISFACTION?

THREE OLDER ADULTS LIVING WITH HIV SHARE INSIGHTS ON LOVE, SEX, AND DATING

BY MARK S. KING

THE VERY IDEA of maintaining an active sex life with our partner into our golden years—much less finding that partner in the first place—is an often unspoken anxiety that is only multiplied for people living with HIV. The challenge often begins with HIV disclosure itself, and extends to the physical demands of aging that can impede desire and sexual response.

I spoke with three HIV-positive seniors who have navigated the sexual terrain; their experiences range from adventurous, to romantic, to a happy dismissal of sex altogether.

ROB
‘There is a difference between sex and love’

WE’RE NEVER TOO OLD for life to teach us something. For Rob de Groot, a 73-year-old man from the Netherlands, an unexpected sexual adventure provided an important lesson for him and his partner about what they truly valued in their relationship.

Rob, who has lived with HIV for 30 years, had found himself “incapable and uninterested” in sex prior to meeting his partner six years ago. But Rob’s new boyfriend was nine years younger and “had not been able to turn off that switch,” as Rob explained. Before long, Rob’s partner began a sexual affair with a younger man, leaving Rob devastated.

“I was afraid he would leave me,” Rob said. He also wanted to meet his “competition.” This was arranged. “Then I found out that this young man was also interested in *me*! So, at 67 years old, I had a couple of threesomes.” Rob took part because he wanted to demonstrate to his partner that “there is a difference between sex and love.

“Luckily, he came to understand the difference, and the affair ended. It became the most rewarding relationship I have known.”

Rob lost his partner suddenly three years ago, along with the intimacy that their foray into sexual adventurousness had helped create. “I miss him coming up behind me while brushing my teeth,” he says wistfully, “and feeling his arms around me.”

Rob accepts his advanced age without romanticizing it. “I know that, at 73, I am an old man that is still interested in life around me,” he said. He devotes his time to serving as a mentor to younger people living with HIV.

“I may be an old physical wreck,” said Rob, “but I never complain about that, especially to younger people.”

TIM PATTEN: CHRIS POWERS ROB DE GROOT: EWOUD BROEKSMA ASHA MOLOCK: FREEDOM G PHOTOGRAPHY

ASHA

‘We deserve intimate relationships’

ANYONE WHO FEARS that seniors living with HIV are beyond romantic possibilities can take heart in the story of Asha Molock. The 65-year-old woman from Philadelphia is being courted by someone special, and love might be in the air.

“We have known each other for 10 years, and he already knew about my HIV status,” Asha explained. “He treats me with respect.”

Recently, the two friends talked about getting more serious. “I was hesitant at first,” she said, “not because of my HIV status, but because I didn’t want to ruin a good friendship if it didn’t work out.”

They are taking things slowly, but fans of the terribly romantic will be pleased to know that the couple have held hands and kissed. Should things become more physical, “there will be no fear of intimacy from either of us,” said Asha. “We talk about HIV a lot, and he understands how it is transmitted and what it takes for us to be safe.”

For a time, fear of HIV criminalization kept Asha from “even thinking about trying to have another relationship.” In a majority of states, there are HIV non-disclosure laws that have been used to target people with HIV, even if a condom was used or the person with HIV otherwise posed no risk of transmission.

“People with HIV deserve intimate relationships,” she said, “no matter what age. Having been married twice, I don’t desire to get married again, but having companionship and intimacy is important to me because I am human.”

Asha’s words of advice for elders? “Make yourself a priority,” she said. “Don’t feel guilty about being a little selfish and spending time on yourself. We live in a society where the elderly are ignored, and adding HIV to that can make life more difficult. Turn up your life, don’t isolate yourself, and get out and socialize!”

Asha takes her own advice to heart. “I plan to live my life like it is gold,” she said confidently, “way into my golden years.”

TIM

‘Sex was my hobby’

AFTER DECADES of what he describes as an exhausting pursuit of sex and dating partners, 64-year-old Tim Patten made a decision to stop having sex altogether. It is a choice he believes has made his life significantly more satisfying.

“Sex was my hobby,” said Tim, a gay author and financial adviser from San Francisco. “I have transitioned from someone who needed sex as a way to make me feel good about myself to someone who is in love with my creativity and generosity toward others.

“I thought sex made me feel like a man; but today I know I am a man, making contributions to others in much more amazing ways,” he said.

Tim began to experience some sexual changes several years ago. “I was having fewer erections in the morning,” he said. “I had little of the nagging desire to have sex or masturbate. When I realized this, I made a mental decision to stop cruising, dating, or watching porn. Today, I still love that sex has no hold over me. I have discovered friends, giving, and writing. I’ve written four books and dozens of articles on the web over the past seven years.”

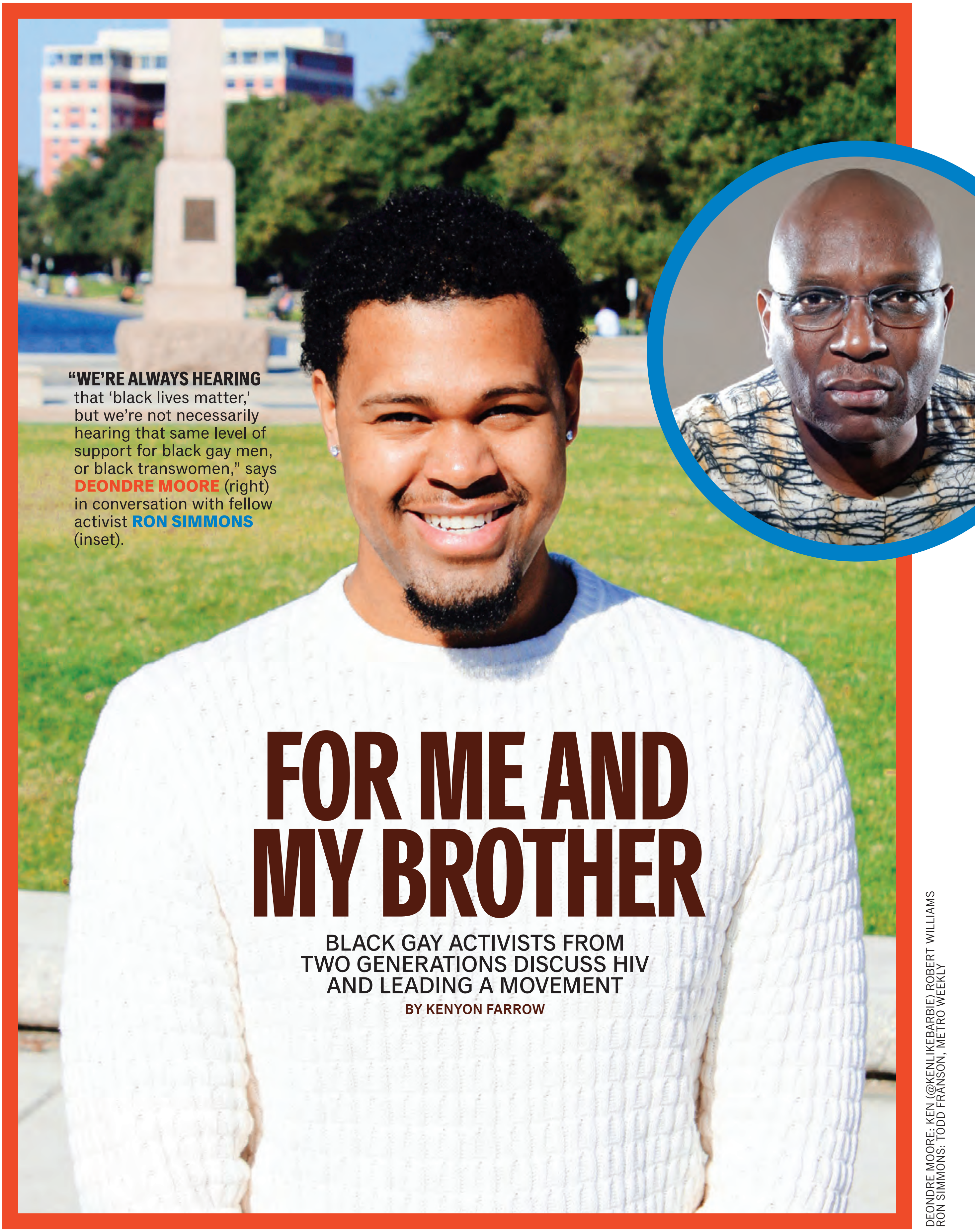
Tim knows that he has rejected sex amid a culture that values sexual prowess, but he has no regrets. The rewards to his time and focus have been considerable. “I have helped young friends in their 20s find their way into careers, loves, and marriage. I helped them write resumes, cover letters, and practice job interviews. I have helped young men in other countries cope with HIV at very young ages.

“Growing and changing is the best part of living,” said Tim. “I absolutely love this part of my life.”

FOR ME AND MY BROTHER

BLACK GAY ACTIVISTS FROM TWO GENERATIONS DISCUSS HIV AND LEADING A MOVEMENT

BY KENYON FARROW



“WE’RE ALWAYS HEARING that ‘black lives matter,’ but we’re not necessarily hearing that same level of support for black gay men, or black transwomen,” says **DEONDRE MOORE** (right) in conversation with fellow activist **RON SIMMONS** (inset).

DEONDRE MOORE: KEN (@KENLIKEBARBIE) ROBERT WILLIAMS
RON SIMMONS: TODD FRANSON, METRO WEEKLY

“Black gay men’s lives cannot solely be dealt with around HIV.”

—RON SIMMONS

WE’RE ALL FAMILIAR *with the recent headlines: One in two black gay men is likely to become HIV-positive in his lifetime. Countless conferences and meetings have been convened to figure out how to better “target” this community to be tested for HIV and linked to care. Many testing campaigns implicitly tell black gay men to treat one another with suspicion, rather than as sources of support or strength. Often HIV prevention programs and support groups divide us up—positive and negative, youth and elders.*

But black gay men are more than just their HIV status. There is a rich history of black gay men working not only as service providers, but also as activists. And as many black young people, straight and LGBT, mobilize around the country to respond to racism in the criminal justice system, the time is now for black gay men across generations to dialogue about how HIV fits into a social justice agenda.

What lessons can we learn from black gay elders, drawn from the past 35 years of political and cultural work? What can black gay youth teach us about resistance that can be harnessed into a new movement to end the epidemic for black gay men?

I spoke with two activists living with HIV—Ron Simmons, PhD, 66, president and CEO of Us Helping US: People into Living, Inc. (UHU), in Washington, D.C. and Deondre Moore, 21, Greater Than AIDS ambassador and student at Sam Houston State University in Huntsville, Texas—to hear, from their perspectives, where activism fits into our work to change the course of the epidemic for black gay men’s lives now.

Tell me how you became an activist.

RON SIMMONS: I became an activist in college in 1969, when we had the student strike against Richard Nixon bombing Cambodia. That’s when I really became something more than a regular college student just going to my classes. I started to go to meetings, organize things, become a spokesperson, things like that. Then I got involved in the gay movement on campus—at the State University of New York in Albany.

DEONDRE MOORE: Before finding out I was HIV-positive, I always looked at myself as a leader among my peers, and usually took the lead role in projects like student government organizations in high school. So after finding out my status, there was a feeling in me that led me to believe that I could use my voice to end this epidemic that, I always say, should have ended before I was born.

I started sharing my story in church. After that, someone at church saw me that day and heard my testimony, and notified me about a campaign they’d heard about that Greater Than AIDS was putting on in Texas. I applied and was accepted. And I’ve used every platform since to make my voice heard to share what I’ve learned with my community.

Ron, you’ve said before that you didn’t become involved in HIV until some years into the epidemic. Can you tell me what you were doing in the early days of the epidemic, and what brought you into HIV work?

RS: I was working with Sydney Brinkley doing *Black Light*—the first black gay magazine in the country. I didn’t get involved with HIV until I became positive in 1990, and then I joined Us Helping Us in 1991, and that’s when I began to get active in HIV prevention and holistic health among gay men.

Deondre, what do you think are the most critical issues facing black gay men today?

DM: I think there aren’t enough role models or mentors. And we still face acceptance issues in the larger black community. We’re always hearing that “black lives matter,” but we’re not necessarily hearing that same level of support for black gay men, or black transwomen.

RS: I’ve heard the black women who are the leadership in Black Lives Matter speak specifically about black women, black transwomen, and all aspects of the black community mattering. But that’s been hard for many people in the community to adopt. When you find yourself in total chaos, it takes a while to develop that kind of intersectional thought.

The Centers for Disease Control and Prevention (CDC) just released new data showing black gay men have a 1 in 2 chance of acquiring HIV in their lifetime. What was your reaction when you first heard this?

RS: Frankly, I didn’t react to it. Ten years ago in 2005, the CDC related that study that 46 percent of black gay men in five cities were HIV-positive. So this new information didn’t faze me in a way, because I remember a death every seven to 10 days and people walking around with Kaposi sarcoma, when it was a real nightmare. I remember those days. And today we’re down to one pill a day, and people may think these statistics are a nightmare, or hell. Well, I remember what hell was. If half of us are positive and can take one pill a day, that’s better than half of us being positive and dying in the streets—which may still happen if they take this health care away.

DM: I wasn’t surprised as well. We’ve known that black gay men have always been at higher risk for HIV since the beginning. We need to take a step back and analyze what we’re doing and ask ourselves if it’s making a difference. People have been fighting this fight for over 30 years, they’ve launched different initiatives, all the funding they’ve gotten; people have gone through these programs to promote safer sex. It’s confusing as to why, 30 years later, our chances of getting HIV are even higher, even if we aren’t dying. And something has to change to make these initiatives more effective.

RS: We do know the research shows that the high rate of HIV among black gay men is not because we’re running around fucking like bunnies without condoms. Some of it is simply a question of odds. Because of racism and preference, black gay men tend only to have sex with other black gay men. If you’re saying that half of us are infected, unless you use condoms 100 percent of the time (and no one does), the odds are against you.

It’s not about we don’t care about ourselves or we don’t care about each other. What we’re finding at Us Helping Us, and it’s true in some of the new studies, is most of our clients [who became HIV-positive] were in love, in a relationship, and either the other person didn’t know their status, or people thought they were in

> 'The main problem for black gay men is not HIV; it's that we're trapped in a racist, homophobic, capitalist society. If I'm at a table where the only thing we're gonna talk about is HIV, but we're not gonna talk about unemployment, housing, education, and the criminal justice system, that's not gonna work because WHAT'S AFFECTING US IS *EVERYTHING*.'
>
> —RON SIMMONS

monogamous relationships and it turns out they were not.

DM: I agree with that. That sounds like my situation, because when I tested positive it wasn't that I didn't care about myself. Before my relationship I got tested, it was negative, and it turns out my partner lied and had known he was positive for five years.

What is the responsibility of black gay men to organize to challenge the CDC, the local health departments, health providers, churches, and school systems?

DM: We need to make sure we have a seat at the table to let people know if these programs and things aren't effective. And if there isn't a seat at the table, you need to create one.

RS: The main problem for black gay men is not HIV; it's that we're trapped in a racist, homophobic, capitalist society. If I'm at a table where the only thing we're gonna talk about is HIV, but we're not gonna talk about unemployment, housing, education, and the criminal justice system, that's not gonna work because what's affecting us is *everything*. You can be HIV-negative, but you can be unemployed. You can be HIV-negative, but you may have to sell your body to survive.

Why don't we see these kinds of issues in workshops, keynotes, community projects hosted by black gay institutions, and reflected in a broader black gay political agenda? Why don't we see black gay prides where people march on city hall or the health department?

RS: The idea that there would be government money going toward "Negro homosexuals" to be Negro homosexuals was unheard of until AIDS came along. The idea that we would have conferences or travel the world, and have begun to meet and see each other and build a national infrastructure, only happened because of HIV. Had it not been for HIV, we would have had no resources going to us.

We've had almost 20 years of CDC-funded interventions targeting black gay men to engage them in testing, behavioral interventions, linkage to care, and now, PrEP. What do you think has been successful? What do you think these programs have missed?

RS: Looking at the programs at UHU, most of which have been validated by the CDC, most are effective to some degree. They all have a part they play. But black gay men's lives cannot solely be dealt with around HIV. One of the most effective programs is the MPowerment intervention, and these young brothers come up with some great projects; but again, it's limited.

The CDC is not gonna give you money to march on city hall to demand housing—even though housing would be critical in dealing with HIV. Same thing for unemployment.

DM: Another thing that's been working for me is speaking out. I went to a conference Human Rights Campaign puts on every year called Time to Thrive, and it's for educators and people in youth service professions. The audience didn't look like me; in fact, the two workshops targeting African Americans ended up being canceled. But I spoke about how I was failed by the sex education system in Texas, and I called out the National Education Association on their bullshit. Even though we know HIV rates are high among youth in the South, we still fund abstinence-only education.

Let's say we can end the epidemic among black gay men in 10 years. What do you think it will take us to get there?

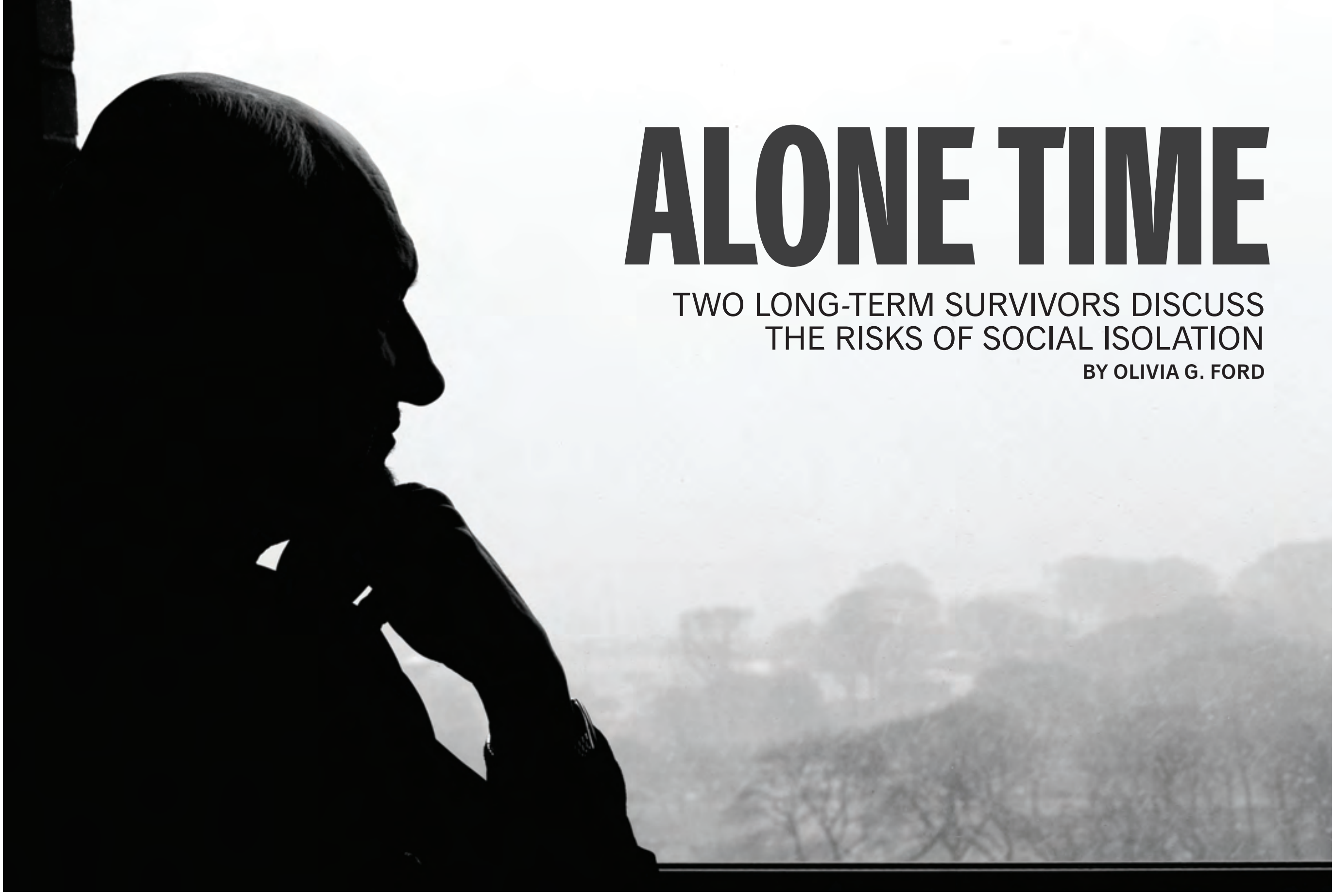
RS: We have to look at it as more than HIV. We have to educate each other, and we have to look at it as: *It's not about me, it's about my brother.*

Although years ago I never would have said this, I think we need to look at PrEP. We need to do something that breaks the new infections for at least two or three generations. You know how I feel about the pharmaceutical companies, but I think we have to try a biomedical approach for at least a generation or two.

DM: It's gonna take us acting up again. We have to act up with research institutions, pharmaceutical companies, and others. Like I said, 30 years later and people have made a lot of money off of HIV and we still have the rates of infection that we do. Something has to change. And we're gonna have to act up again.

KENYON FARROW is an award-winning writer and activist, and the U.S. and global health policy director for Treatment Action Group. He has worked on campaigns that bring together HIV, criminal justice, and housing policy issues focusing on black and LGBTQ communities.

PHOTO: DERRICK WATKINS, DW PHOTOGRAPHY



ALONE TIME

TWO LONG-TERM SURVIVORS DISCUSS THE RISKS OF SOCIAL ISOLATION

BY OLIVIA G. FORD

PHOTO: ISTOCKPHOTO

PEOPLE NEED HUMAN CONNECTION in order to survive. As people grow older, a chipping away of connections to social life often leads to isolation from family and community.

According to research compiled by the AARP Foundation, the negative health effects of social isolation among older adults rival those of smoking and obesity. Older adults living with HIV are particularly vulnerable to isolation in part because they are more likely to live alone than the general aging population.

I sat down with **Gina Brown, MSW**, and **David Fawcett, PhD, LCSW**—both social work professionals and long-term HIV survivors, and both active with the HIV/AIDS and Mental Health Training Resource Center—to talk about the ways older adults living with HIV find themselves socially isolated, and what can be done about it.

How does social isolation happen?

DAVID FAWCETT: I think a lot of older people living with HIV, especially in the gay community, may feel less energetic, less attractive, and invisible in the community. That can result in isolation.

Also, despite surviving so long with HIV, I think many of us have side effects from the medication that impair our ability to go out and socialize. Even though people are basically healthy, there may be residual effects from the years of drug trials and that kind of thing.

GINA BROWN: As a woman who is 50 and living with HIV, I'm also starting to feel some of that isolation and that loneliness. People say, "Go out and mingle." But where do you go, and who do you mingle with?

As we get older, the younger people around us have their own lives. Your siblings pass away. That causes older people to be even further isolated, when family is not even around. So, they rely on the HIV community.

DF: That's exactly the experience I've seen. For a lot of the older gay men I work with, I'm surprised at how damaged the family relationships were from way back. Those relationships never really healed, so they're living without that natural family support. It falls to them to create a chosen family.

Then there's a complicating factor with substance abuse, where a lot of people have burned bridges with their families before they got well. I think that contributes to this lack of biological family support systems.

GB: Transportation can be a factor in isolation as well. It's been more than 10 years since Hurricane Katrina, but New Orleans is not back to the way it was before the storm. A lot of bus services didn't come back in some areas, and it's hard for many older people to get around.

DF: When I work in the Florida Panhandle, there are people up there who are hours from any kind of medical provider, and many lack transportation. They may just give up on trying to get services. I think particularly in the South, it's just horrendous.

People living with HIV often experience high levels of trauma and PTSD (post-traumatic stress disorder), both before and after they test positive. How does trauma contribute to isolation?

DF: The experience of living with HIV from my generation, and Gina's generation, is very different than the experience of younger people getting diagnosed today. There are tremendous amounts of loss and grief, and a feeling that the experience that we had is not acknowledged.

I see a lot of people self-medicating from the effects of trauma—and not just with recreational drugs. I think there has been a tendency for physicians to over-prescribe to people living with HIV. Many of my clients have standing prescriptions for tranquilizers, sleeping pills, pain pills. Traditional medical providers may not understand the link between trauma and some of the symptoms they're seeing. That falls to members of the mental health community, who may also be really ill prepared.

GB: I am one of those older adults who has survived not only childhood molestation, but also intimate partner violence. I'm in therapy. I have a great support system. But think of all of the women who never tell anyone that this happened to them, and never work through it.

I often talk about needing to take a step back and look at the HIV community members we see as loud, or angry, or combative, as possibly having some kind of unaddressed trauma.

DF: I agree: Trauma is a desperately needed focus that we must address, both in terms of how it's driving new infections, and how it's affecting the quality of life of people living with HIV.

How can community organizations support mental health and prevent isolation?

DF: As HIV has become mainstreamed as another chronic medical condition, a lot of the things we had in the early days, like buddy programs, have fallen by the wayside. More of these programs would be tremendously valuable.

In my community, we have a program now where people will walk someone else's dog, or there may be money to take their dog to get vaccinated if the owner can't afford it. Dogs can be essential for mental health.

GB: In New Orleans, there aren't many senior citizen centers around anymore, so older adults can't even go and hang out with people their age. I would love to see some safe spaces just for them.

In a perfect world, we would really take care of our elders. We would really respect them; all that they've given to the world, we would give back to them.

DF: We have a very large gay and lesbian community center here. They do a coffee meeting on Tuesday mornings geared toward people 70 and older. They get 200 people; sometimes it's the only outing these people have all week, and it's fabulous. It doesn't have to be expensive or complicated to present opportunities for people to connect with each other.

Is there a role for advocacy—or networks of people living with HIV—in combating isolation?

GB: For some of the advocacy networks like Positive Women's Network-USA, that have older people as members or on the board, the older people have to drive the conversation and make sure that our issues are on the table. We have to make sure that we're educating young people on the things that are happening with older people.

Those of us who are growing older with HIV, or who were diagnosed at an older age, need a place and a voice. There are places that are already set up, so we don't have to reinvent the wheel.

DF: I think there's a fatigue that comes with living with HIV for so long. I'm a great believer in purpose. I think a lot of older people living with HIV may have lost their purpose, or can't identify with it. It's wonderful to give people opportunities to come together, to keep having these conversations, to acknowledge their experience and their value, which I think they themselves don't recognize.

What advice do you have for anyone working with older adults living with HIV?

GB: When I worked as a social worker, I would always remind the other case managers that for older people, especially older black people, respect is big. If it's Ms. Jones, call her "Ms. Jones," not by her first name.

DF: Another thing would be to reconnect with our compassion and empathy for what people have gone through—not just in surviving, but in many cases thriving, and now starting to deal with the other complications of age.

GB: Compassion and respect are huge. All humans want that. But as we get older, it becomes even more precious.

Five facts about social isolation

Adapted from research by SAGE and the AARP Foundation

Isolation can change a person's health outcomes. Studies show that isolated older adults are much more likely to die from chronic diseases such as breast cancer or heart disease than the general aging population. Loneliness and social isolation can affect the immune system and inflammation levels and disrupt stress hormones.

Instability can contribute to isolation. This is true for older adults in general, but LGBT elders deal with higher rates of disability and economic insecurity, as well as mental health concerns – all of which may be rooted in lifetimes of discrimination. Major life transitions like a loved one's death or a lost job can also contribute to loss of stability.

Isolation also has an impact on caregivers. Being a caregiver to another person can contribute to isolation. The number of people providing unpaid care is rising in the U.S. – and these caregivers are most likely to be women. Caregivers often are alone in their work; have less time for friends and family; and are less likely to care for themselves by seeing their own health care providers or watching their diet and exercise.

Affordable transportation and accessible streets are key to combating isolation. When older adults cannot travel on their own, risk for isolation and declining health increases. People in places that do not have adequate public transportation are much less likely to connect with friends, health care providers, and activities.

Policy solutions can help keep older adults off the road to isolation. Legislation promoting cheap public transportation, "complete streets" that safely accommodate all who use them (not just drivers in cars), and safe and affordable housing can assist older adults in staying connected to community and easing isolation's negative effects.

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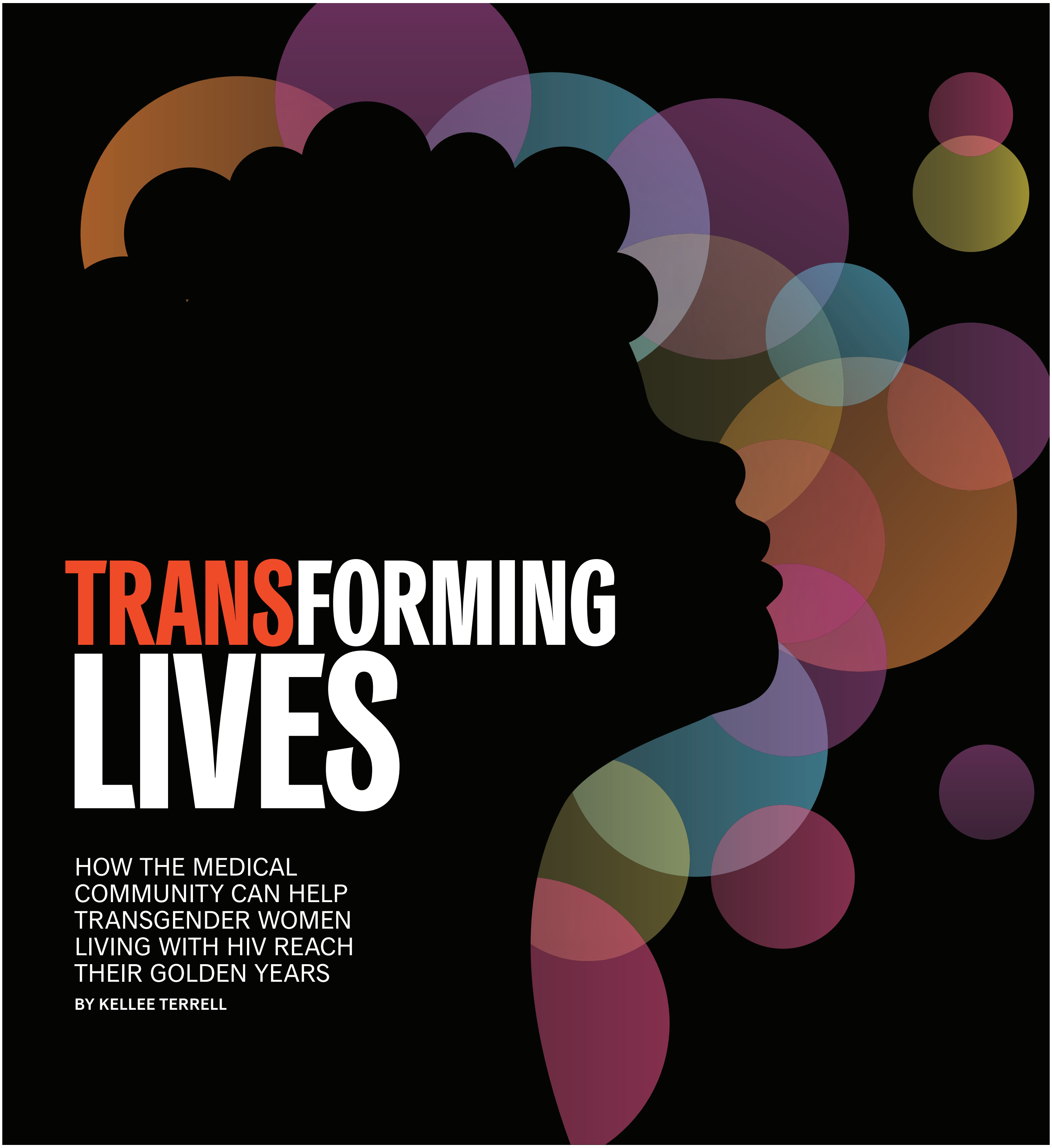

TRANSFORMING LIVES

HOW THE MEDICAL COMMUNITY CAN HELP TRANSGENDER WOMEN LIVING WITH HIV REACH THEIR GOLDEN YEARS

BY KELLEE TERRELL

PHOTO: SISTOCKPHOTO

WITH SO MUCH TALK about aging with HIV, how does the conversation change when gender identity is added to the mix?

Unfortunately, the data around life expectancy and transgender women are shaky at best—and there is painfully little information regarding *any* aspect of transgender men's experience with HIV, much less how they age with HIV. But here are some things we do know: Transwomen are 49 times more likely to become HIV-positive than the general population, have high rates of being positive and not knowing it, and are less likely to be connected to consistent HIV care.

Granted, the same factors that make transwomen more vulnerable to HIV transmission are also the same barriers that keep them out of the health care system, and threaten their lives overall.

"Higher rates of violence, poverty, homelessness, discrimination, and incarceration are structural barriers that many transwomen face on a daily basis," said Cecilia Chung, senior strategist at the Transgender Law Center in San Francisco.

"Even with a rise in trans visibility, stigma, fear, and isolation are also factors, especially

CECILIA CHUNG SPEAKS AT THE ATLANTA LAUNCH OF THE POSITIVELY TRANS SURVEY REPORT AND DIGITAL STORY COLLECTION.

among communities of color," she added. "I still see transwomen afraid to walk into HIV clinics because they don't want anyone else to know their business."

Realistically, these structural fissures cannot be fixed overnight (especially when LGBT/HIV organizations don't always prioritize trans issues). But while advocates continue to work on the grassroots and policy levels, there are actions medical providers can take right now to help extend the lives of transgender women living with HIV.

Understand HIV-positive transwomen's priorities

TOO OFTEN, medical professionals believe that HIV treatment is most important to clients living with HIV, when that isn't always the case. The Transgender Law Center's 2016 Positively Trans survey, which collected data specifically from transgender individuals living with HIV across the U.S., found that HIV treatment was fifth on respondents' lists of priorities.

"Gender affirming health care, personal care, mental health, and hormone therapy were more important than antiretrovirals," stressed Chung, who worked on the survey and is also a transwoman living with HIV.

This is why physicians need to listen to their patients more often, stressed Kate Franza, assistant director of behavioral health and community programs for the Asian & Pacific Islander Wellness Center in San Francisco.

"We must ask them more often what they believe is their greatest need in that moment, instead of having our own ideas of what they need," she said. "This is about creating a partnership and respecting people's life choices."

Link hormone therapy to HIV treatment

GIVEN THAT hormone replacement therapy (HRT) is important, providers should be able to provide HRT and HIV care simultaneously, said Magda Houlberg, MD, chief clinical officer at Howard Brown Health in Chicago, where this is mandatory practice.

"Getting to one appointment is hard enough, but then to say, 'You have to come back to get hormone treatment with another clinician' isn't fair. Providers shouldn't get to opt out; it should be standard," Dr. Houlberg stressed.

Most important, Franza points out that HIV treatment shouldn't be a prerequisite to get HRT either.

"How can you think about treatment if you don't feel good in your body or comfortable in your clothes? If a client wants to talk about hormones first and not treatment, we shouldn't refuse them," she said.

Don't think 'cause you're an LGBT clinic, you're culturally competent

THANKFULLY, MORE and more LGBT clinics across the country have growing trans-specific programs with support groups and drop-in services that offer food vouchers, health care, hot meals, and clothing. But just like traditional medical settings, these clinics also need to work on cultural competency.

"I've gone to my HIV clinic in Atlanta and the front desk staff has misgendered me or referred to me as the [male] name on my insurance card," said Jennifer Barnes, a woman of trans experience who was diagnosed with HIV in 2011. Barnes often wonders: "How hard is it to read my chart and see the name I go by?"

Sadly, these types of experiences, from the front desk to the exam room—even in LGBT- and HIV-specific clinical settings—are not new or rare. "So many transwomen come to these clinics having already experienced a lifetime of medical trauma, and this can retraumatize them, break trust, and push them further out of care," Franza said.

Other ways for clinics to address this disconnect are implementing more education on trans issues for staff, cultivating trans leadership, and hiring more trans employees in all areas of service, including clinical settings. Yet, Houlberg points out that diversity among medical staff is hard to come by.

"Medical providers need to reflect the population, and right now most medical schools just don't," she admitted. "There just isn't enough diversity in these settings, and it's a real problem."

In the end, Franza points to her robust client base of positive transwomen over 60 as proof that it's possible for transgender women to live a long, prosperous life. But medical providers have a part to play in that—and it's pretty basic.

"It's important to be kind and open without judgment," said Franza. "That is truly the best way to serve our community."

KELLEE TERRELL is an award-winning filmmaker and freelance writer who writes about race, gender, health, and pop culture. Her work has been featured in *Essence*, *The Advocate*, *The Root*, POSITIVELY AWARE, *POZ*, *The Huffington Post*, and TheBody.com.

CECILIA CHUNG: COURTESY TRANSGENDER LAW CENTER KELLEE TERRELL: STEVEN DUARTE

PLANNING AHEAD

MAKING THE BEST DECISIONS FOR THE END OF LIFE

BY DAVID DURÁN

PHOTO: ISTOCKPHOTO

There's no avoiding the fact that we can't live forever. Although it may be hard to think about having to plan for the end of your life, it's better to endure the uncomfortable moments way in advance, while these decisions are still yours to make. The reality is, it may not just be about you; when you see it from the perspective of easing some of the stress of the end of your life for both you and your loved ones, it might be easier to talk about your options, and set a plan in motion for when that time does come.

MANY PEOPLE don't take the time to think about their own deaths. That is often not the case for people living with HIV. For long-term survivors who were diagnosed at the height of the epidemic in the 1980s and early '90s, death was a reality that was perceived to be imminent.

"When I first tested positive in 1986, I was told that I had only two years left to live," said Tez Anderson, 57, a champion for long-term survivors. "Soon after getting that news, one of the first things I did was make out a living trust, a will, and a power of attorney, so that I could make the arrangements myself.

"My generation understood the importance of these documents, because for the people left behind, it makes all the difference," he said. "[We've] been preparing for years to die; and although some might be in denial about it, for those of us who saw our friends dying left and right during the crisis, we learned the importance of being prepared."

Kit Kloeckl, 66, was diagnosed with HIV at age 55; his moment of realization came when he was already in the hospital. "In 2005, I became very ill with pneumocystis pneumonia," he explained. "I had been with my partner for a year, but had not put any protections in place to take care of him should I pass away."

At the hospital, Kloeckl attempted to handwrite a will, since his family members were not supportive of his relationship. He was too sick to be able to do so. Fortunately, he recovered; afterward, he consulted with a professional trust attorney to guarantee that his partner would be taken care of if he were to become ill again.

"It's critical to have something in place to ensure your wishes will be carried out, and not be sabotaged by family," Kloeckl said.

Meeting with a professional can be a great step in making end-of-life decisions. There are also many things you can do on your own, simply by creating some documents and signing them in front of a witness.

Another step is to gather your thoughts and consider your feelings and options regarding:

Creating a will: What property will you leave behind; who do you want it left to; and who will execute your will so that your wishes are met?

Creating an advance directive: What kind of health care do you want, or not want, when you cannot make your own decisions? Who should you choose as your **health care proxy** to make sure your desires are respected? What are the guidelines for your state?

Eldercare: Where and how do you want to be taken care of, in the event you are not able to make those choices when the time comes?

Powers of attorney: Who, if anyone, do you want to empower to make legal, financial, or health care decisions on your behalf if you cannot?

Life insurance policies or establishing trusts: Who will be your beneficiary?

Funeral wishes: Do you want a somber gathering? A joyful party? A low-tech "green burial"? How would you like to be honored—and how will it all be paid for?

Organizations like the American Association of Retired Persons (AARP) and the American Geriatrics Society's Health in Aging Foundation maintain a wide range of online resources and printable forms to help guide and organize the process of making these important plans. Many HIV and LGBT organizations also provide free legal clinics or can refer you to pro bono or reduced fee services in your area.

Anderson stressed that if you do have all your documents in order, it's important to review them every few years and make sure they are up to date. "Once you accept that death is a part of life, it makes it all a little bit easier," he said; "and really, being prepared is an act of love for the people you are leaving behind."

Although there will come a day when each of us will reach the end of our life, for those living with HIV, that day is likely much farther in the future than they might have expected. There is now time and space to be thoughtful and proactive, instead of anxious and panicked, about these decisions.

Whether you are a person living with HIV or a person just living, making plans for the end of our lives helps ensure that, when our time does come, those we love won't be additionally burdened—and will know how to give us exactly the send-off we want.

DAVID DURÁN is an LGBT-focused freelance journalist who contributes to such publications as *The Advocate*, *Instinct*, *OUT*, POSITIVELY AWARE, and *The Huffington Post*.

I am a colleague, a mother, and a cook.
And I am living with HIV.

Let's stop HIV together.™

—Barbara

Barbara (right) has lived with HIV since 1983.

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