

The Graying of **AIDS**

Stories from an
Aging Epidemic

by Katja Heinemann
and Naomi Schegloff, MPH

When you imagine a person with HIV or AIDS,
what do they look like?

The Graying of AIDS

BLACK OR WHITE, GAY OR STRAIGHT, the face that most Americans imagine when they think about HIV/AIDS isn't particularly wrinkled. Yet approximately one quarter of the people living with HIV in 2005 were 50 or older, and studies project that by 2015 more than half of all people living with HIV in the US will be over 50.¹

The aging of HIV/AIDS reflects the merging of two different populations. People with HIV are living longer thanks to advances in medical treatment like the development of highly active antiretroviral therapies (HAART). At the same time, some people over 50 continue to engage in high-risk behaviors that result in new infections. Many older adults don't know how to protect themselves from HIV—or even that they can be at risk—in part because few health education materials have prioritized their unique experiences and concerns.²

This lack of attention to the prevention needs of older adults is just one indicator of the health care community's collective assumptions about who is and is not at risk for HIV. (Note: Since the early days of the epidemic the term "older adults" has consistently

been used to describe people aged 50 and older.) Few training programs for providers have addressed the aging of the epidemic.

Surrounded by sanitized, asexual depictions of older people in our popular culture, many providers don't think to conduct thorough sexual and substance use risk assessments when collecting medical histories from patients over 50. As a result, some of the possible indicators of HIV infection—including muscle and joint pain, night sweats, and extreme fatigue—may be written off as simply a part of "getting old." This oversight can have serious implications for patients: detected early enough, an HIV diagnosis can be the first step in managing a chronic infectious disease rather than the "death sentence" it once was, while delays in testing, diagnosis, and care can result in significantly worse health outcomes. And as older people with AIDS become less able to live independently, few assisted living and nursing facilities are equipped and staffed to adequately address their needs.

A surge in research on HIV and aging is illuminating critical gaps in knowledge and services and precipitating important changes in the field. Much

of the earlier work on the graying of the epidemic targeted specific cross-sections of the population or particular behaviors, like condom use; while these studies improved certain aspects of our understanding of aging with the disease, the daily realities of people over 50 living with HIV have been, until recently, largely unexplored.

In 2006, ACRIA (AIDS Community Research Initiative of America) published the initial results of the groundbreaking ROAH study (Research on Older Adults with HIV). Working with a broad network of researchers, health care providers, and AIDS service organizations, ACRIA collected data from a demographically diverse cross-section of 1,000 people over 50 living with HIV in New York City, providing valuable new information about what it means to age with the virus. That same year, documentary photographer Katja Heinemann created a series of portraits and oral histories in which older Americans shared their experiences of aging with the disease. Her photographs and interviews, in conjunction with this valuable new research, are the inspiration for *The Graying of AIDS*, a three-pronged campaign designed to increase sensitivity and awareness about the issues confronting people over 50 at risk for, or living with, HIV and AIDS.

In addition to this magazine, a companion DVD and website (www.grayingofaids.org) aim to educate health care and social service professionals about this aging epidemic while connecting people over 50 and those who care about them with basic information, terminology, and resources. Despite decades of public health campaigns, myths about HIV/AIDS persist and have serious implications for people at risk for or living

with the virus, so baseline information has been provided to address some of these concerns while simultaneously acknowledging some of the unique challenges that confront HIV-positive people as they grow older.

As the epidemic enters its fourth decade, we must refocus some of our resources and efforts to address shifting demographics, rethink our prevention education strategies to avoid new infections, and revise approaches to service provision to ensure early diagnosis and consistent access to comprehensive, sensitive, and coordinated health care and social services.

Most of the people profiled in this project were diagnosed as HIV-positive early in the evolution of antiretroviral medications, and their stories reflect the realities of long-term survivors who have lived through those changes. While a “positive” diagnosis today brings many challenges, medical treatment has become significantly less complicated and unpleasant. In many ways, aging with HIV today is much like aging without HIV, although there are some critical medical and sociological differences. We are grateful to those who shared their stories and insights with the project for helping us understand these differences and similarities, and for their generosity, candor, and humor.

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Projections suggest that by 2015
more than 50% of all people
living with HIV in the U.S.
will be over 50.

Bill Rydwels, age 77

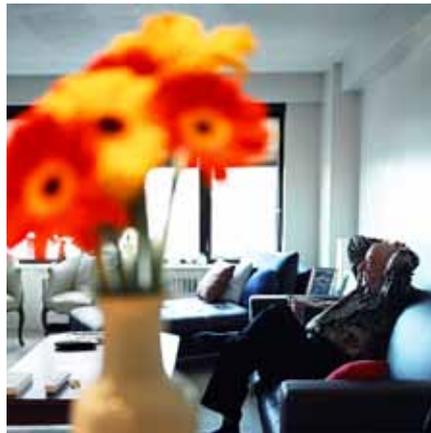
Chicago, Illinois

NO MATTER WHAT WE DO, sex is a beautiful gift, because it is such an exhilarating feeling, and it's such a positive way of getting the feeling that I am wanted and loved in this world. And it's what we all want.

In the beginning it was terrible. I was diagnosed in 1985, and the life expectancy was eighteen to twenty four months. I was in a relationship and unfortunately within seven months he was dead... We were pariah at that time. You don't want to dare tell anybody because they think terrible of you.

I never told my mother I was gay. She knew. She says: "What did your friend die from? Did he have AIDS? Do you have AIDS?" And I said: "No, mom, I have HIV." "Well, that's the same thing." And no, I informed her. Well, she lived in a senior residence, she had friends. She said: "Please, don't tell them. Because they won't come around."

And among seniors it's still that way. They are not educated as to how it is transmitted. So they have fears of eating from plates that people have, shaking hands, using the same bathroom. And none of these are ways of transmission,



In the beginning it was terrible.

but sometimes the wrong things we believe stick with us more readily. Because it's easier to want to believe that if I don't touch that doorknob I won't get the disease.

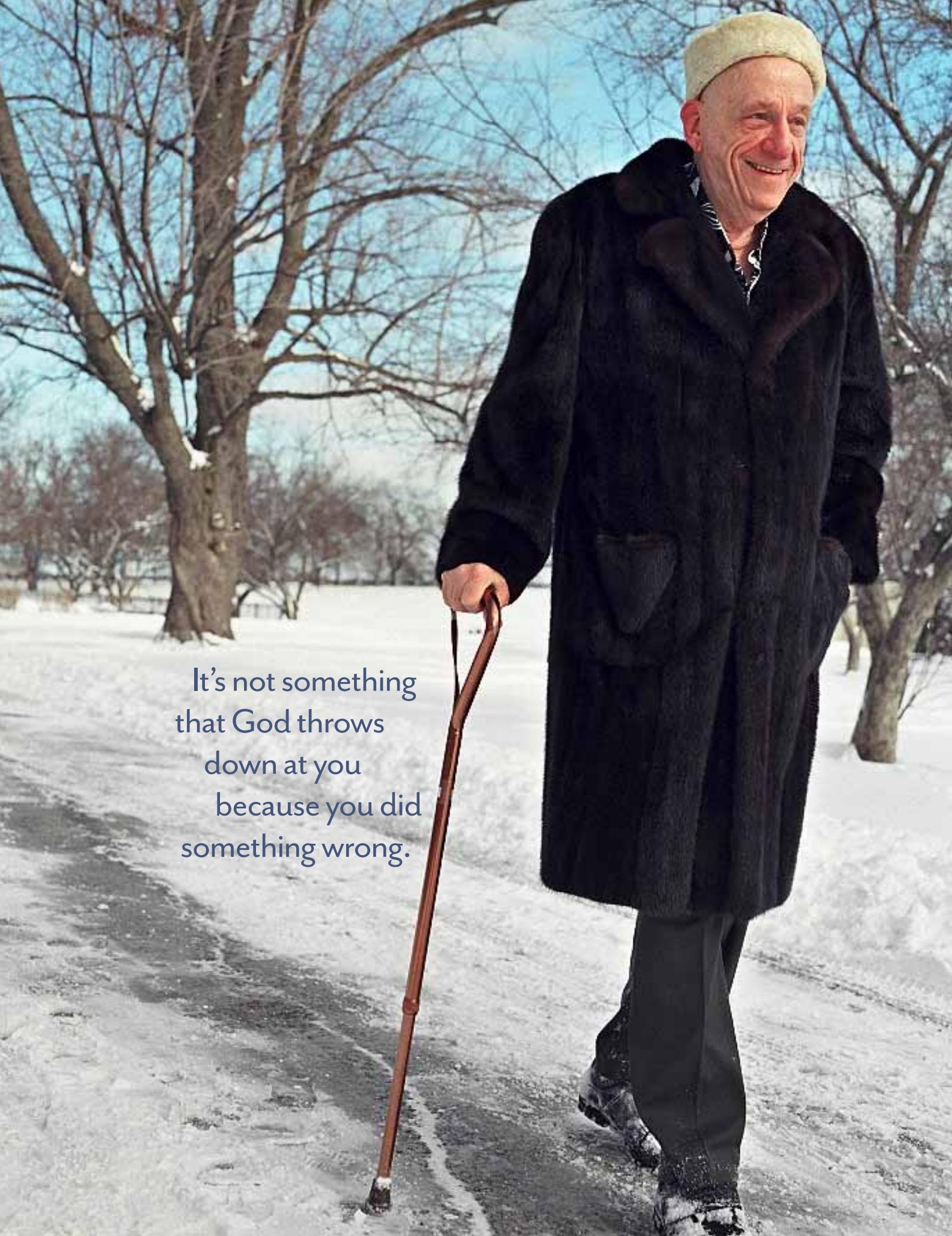
This is just another illness in life. It's not something that God throws down at you because you did something wrong.

We lost magnificent people. I pray every day and I feel that in my prayer I have to mention the names. I mention seventy names every day but there are hundreds of others who died. And the sad thing is that the people who are

dying today don't get their names mentioned. It was a terrible time and a wonderful time, because you got to know everybody very, very well. They cried on your shoulder and laughed with you and today it's not that much.

Don't know what the world would have been like if we had these people and had all the wonderful things they had to offer us. Unfortunately, the drugs weren't there then. We don't have to lose those beautiful people today, because we have the drugs to hold them. Give them a little better health. Or maybe, if you get the right education, prevent them from becoming infected. Young or old, everybody has something to offer. Just give them the opportunity.

AUTHORS' NOTE: ALL ORAL HISTORIES HAVE ONLY BEEN EDITED FOR LENGTH AND THEREFORE REFLECT THE WORD CHOICES AND SPEECH PATTERNS OF THE INDIVIDUALS PROFILED.

An elderly man with a joyful expression is walking through a snowy landscape. He is wearing a thick black overcoat, a white knit hat, and dark trousers. He holds a wooden cane in his right hand. The background features bare trees and a clear blue sky. The ground is covered in snow, with a path leading through it.

It's not something
that God throws
down at you
because you did
something wrong.

Louis and Rosalia Curbelo, age 51 and 47

Fort Lauderdale, Florida

Louis: She took a chance with me. It's funny, I'm positive, but I didn't wanna ask a woman that was negative if they would like to go out with me, because of the rejection that I might get. But then I noticed, I was feeling alone. And when I saw her for the first time, I said you know what? I'm gonna take a chance, I'm gonna ask her.

Rosalia: And I said no. I said, no, but then later on ...okay, you can continue...

Louis: ...but later on I decided, yeah well, I'm not gonna let that NO stop me, and I waited a week, I think, and I asked again, and she

said yes. And we had a coffee, and we spoke, and we took things slow. And it was very nice, because I finally had somebody to talk to. I have family, but it's different. There's some things that you want a partner to talk to. So we known each other for about 6 years and then that's when we decided to get married.

Rosalia: I proposed. He was like kind of smiling, and I think I convinced him.

Louis: My daughter was born in 1987. She was born with some complications, and the doctor needed to do some blood work on the parents. And that was the same day I found out I was positive. My wife at that time, she was negative, and my baby came out negative, also.

When I told my wife she told me everything in the book. She actually tried to see if it could work, and she got help, and counseling, but our connection as husband and wife ...touching her, and trying to get passionate, it scared her, and I could understand. We left on good terms.

Rosalia: I have a lot of respect for her. I cannot even imagine. At that time, 1987, it was like AIDS equals death. For a married woman, recently with a child, and then discovering this? When I met Louis, you started getting more information, it's different than in the nineties. I didn't see him as a person with HIV, I see him first

It's funny that it
took the HIV
to change my life
to a positive.

—Louis Curbelo



as a man, and then okay, I know he have a condition, but I know there's a way to protect yourself also.

Louis: Then in 2004, I woke up very depressed, very depressed. I had my wife, which was good, but I was still missing something. I was looking at my life and I was wondering if this is gonna be it? There was a lot of things that I couldn't do like I used to do. I wasn't working, because I get fatigued. At that moment I took one of the congas and I started playing. And after a while I noticed that I wasn't feeling the same. Afterwards I realized it was a conga that was from a very good friend of mine, and he passed away of HIV/AIDS. And that's when I said, you know, I can't do too much, but maybe I can do this. Maybe I can give something, even for a little bit, it could maybe change somebody's life.

When she got home I told her: "How you feel about maybe making music, with a message. You know, something that could give me new life." And she told me "¡Sí papi, cómo no! Let's do it. Let's go for it." So I said okay, this could become something.

Rosalia: We come up with a name, the concept of Los Doctores.

Louis: We figured a doctor is a person that wants to help people. 'Cause we want to send a message to make the people feel good: As education, and also as a prevention tool. We have lyrics about protection.

Rosalia: Also about abstinence, condom use and testing.

Louis: We know the HIV is there, and we have to deal with that, but we try to not let that lead our lives, and stop us from doing other things.

Rosalia: Sometimes I worry, even if he gets like a flu, or when he's fatigued: he have a condition, Rosalia, sooner or later maybe something can happen. Maybe not, maybe he can be very good for many, many years. And I hope that's the way it's gonna be, but I do worry.

What we're doing now has helped us tremendously, as a couple, because we're doing something creative, we feel we're doing something



good. And I think this is gonna be part of his memory, my memory, his daughter's memory. At least we're leaving something. He's leaving something.

Louis: It keeps me going, because it gave me a new life. My past is my past. It's funny that it took the HIV to change my life to a positive, because through the drugs and the alcohol, I wasn't too happy with myself. I left my daughter when she was two years old. I couldn't take that emptiness. I didn't want her to think of me like that, like I was a dad that just didn't care about his kid. So doing this is just something that I can hope she can be proud of me one day.

Sex and Dating

WE MAY NOT TALK ABOUT IT or see it on movie screens, but sex and romance continue to play an important role in many people's lives as they age. Some who have lost a long-term romantic partner are starting new intimate relationships for the first time since the HIV epidemic began. And some older adults have multiple partners or may be involved with someone who is not monogamous.³ Widespread availability of sexual enhancement drugs like Viagra have made it possible for many men to be more sexually active as they age.

At the same time, many older people have a limited understanding of HIV/AIDS and may assume that only younger people are at risk. In reality, *anyone* can be HIV-positive. It isn't possible to determine a person's HIV status just by looking at them.

HIV infection only occurs when the virus has a direct pathway out of the body of a person who is HIV-positive and into another person's body. Breaks in a person's skin and mucous membranes in the vagina, penis, anus, and rectum can act like open doors for the virus to pass through. Sexually active older women need to be especially careful about HIV: because the walls of the vagina thin and natural lubrication decreases with age, the tiny tears that can result from friction during sex become more common, increasing the risk of HIV infection. People who have anal sex face similar risks. Used correctly, a male or female condom made of latex or (for people with latex allergies) polyurethane can act like a wall that stops infections from passing between people. Water-based lubricants ("lube")—available at most drug stores—can prevent both the tearing of delicate skin and the breaking of condoms.

Whatever their HIV status, people can still enjoy a great sex life as they age, but they do need to use a condom or other latex barrier (like a dental dam) to protect both their partners and themselves.

- If sexual partners are “sero-discordant” (have different HIV statuses), condoms can help keep HIV-negative partners from becoming infected with the virus.
- If all sexual partners are HIV-positive, condoms can protect against the possibility of cross-infection with a different “strain” of the virus.
- Condoms also protect everybody—no matter what their HIV status—from other sexually transmitted infections (STIs).

Even though condoms, when used correctly, have been proven to be an effective form of protection, many older people don't use them consistently: a 2007 study found that only 18% of HIV-negative and 58% of HIV-positive sexually active men ages 49-80 said that they “always” used condoms.⁴

There are many reasons older adults may not use protection. They may, for example:

- no longer need to worry about pregnancy (for straight couples)
- worry about loss of sensation and erectile dysfunction
- not feel comfortable talking about safer sex
- have sex under the influence of drugs or alcohol, which can affect both their judgment and their communication skills.⁵

Some older adults with HIV/AIDS choose not to have sex at all. In addition to fears of infecting others or exposing themselves to other types of infections, some choose to be celibate because of shifting priorities or a decreasing interest in sex; negative body image; difficulty with sexual performance; and feelings like anger, distrust of potential partners, or fear of possible rejection.⁶ Whether or not they are sexually active, many older adults long for relationships, as both sex and dating can be vital sources of comfort, companionship, and human touch.

FOR MORE ON HOW HIV IS TRANSMITTED, SEE [MODES OF TRANSMISSION, PAGE 38](#).

**There's a
lot of myths
that we sort of
shrivel up and die
and it's not true.**

—Larry McKeon, age 61

I like to see people walking together, man and woman or whatever, hand in hand. I like to see relationships. Every time I see this, I used to feel real bad, I kind of hurt a little bit. Because I like being a couple. —Carnetta Best, age 60

When I talk to senior groups about HIV infection, and I offer a condom and talk about it, the women invariably will tell me:
I'm not of childbearing years any more.
I don't need these.

—Paul Spearing, age 67, Health Educator,
Senior HIV Intervention Project (SHIP)

**He's positive, I'm negative,
so it's like: "Really, they're
married, they're a couple, okay,
something must be working."**

—Rosalia Curbelo, age 47, married to Louis, age 51

I can be probably now the best companion that I've ever been. I can do it better this last time around. And I look forward to that, I look forward for that joy.

—Robert Brewster, age 74

Thomas Jones, 58, & Linda Ryals, 61

Brooklyn, New York

Linda: I look at him how he was, and I look at him now, I feel so bad. Because I remember the vibrant Thomas, you know, not the Thomas that can't hardly get up. He's all skin and bones, and it hurts me just to see how skinny he is.

Thomas: I'm thinking I'm one way, but I see somebody else in the mirror.

Linda: He's ahead of the game 'cause he still got life. Think about all the people that's not here, that had the disease. There was a group of us that used to hang out together, used to get high together, about 50 of them. They're all gone, they're all dead. ALL of them. We are the only two left.

Thomas: Each and every individual was HIV-positive. By the grace of God, she never got infected.

We shared needles back and forth, and she used infected needles.

Linda: 'Cause we been together 36 years. So we did everything together. We found out in 1990 that he was positive. And he was doing great. We didn't think that he would waste away like we had seen other people. How they got thin, real thin, and they looked like skeletons with just skin over them. We never thought, not even in our wildest dreams, that it would happen to him.

Thomas: The same people that I seen that got all skinny and everything, right after that they died.

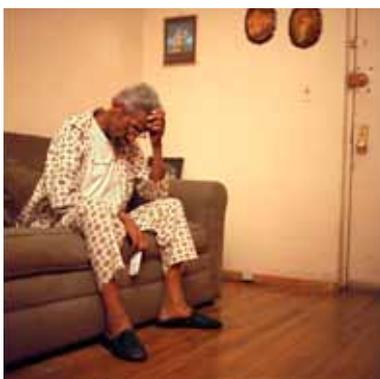
Linda: I thought that only happened to people that was, like, homeless, or wasn't taking care of themselves, wasn't eating or sleeping proper... It didn't really hit either one of us how bad the disease was, because he was still full of pep, getting around and everything....

So then year before last he started getting sick. He had pneumonia. And

we thought that was it. But then he started staying sick. They said that he needed heart surgery, this was last year. And when he went for the surgery, his kidneys failed. So they had to put him on dialysis. He's never been able to bounce back.

Thomas: The doctor told me back in 1990, he said, "At the end, it'll attack your organs." My kidneys are gone, my liver is shot. And my heart ain't worth two cents. I'm walking around with artificial valves, and you know.... I'm pieced all together. All of this stems from the HIV. And I been to the hospital so many times, I know everybody on a first name basis. But I go on, and I say I take one day at a time, but each day go past, it gets worse instead of better.

Everybody thinks that it'll happen to the other guy. You gotta start thinking—you are the other guy. To somebody else you're the other guy. And I thought that and then you see where it got me.



What is she
gonna do when
I'm gone? How will
she survive?

—Thomas Jones

Linda: We're living it. And it's hard, you know, because Thomas and I was separated at the time, when we found out he was HIV. And I said, well that is my husband, and I owe it to him to help him when he's down, because when I was down he helped me.

Thomas: How you think my wife feel, and my kids feel, seeing me sitting here just wasting away? Not even eight months ago, I was 190 pounds. Now, I'm 140 pounds.

Linda: I gotta be the strong one now. He used to be so frustrated, he used to cry. He says, "I'm used to doing things by myself, I'm used

I gotta be
the strong
one now.

—Linda Ryals

to being a man, you know." He says, "I can't even protect you any more." And that bothers him, and of course that bothers me. But we in this together, so, whatever happens...

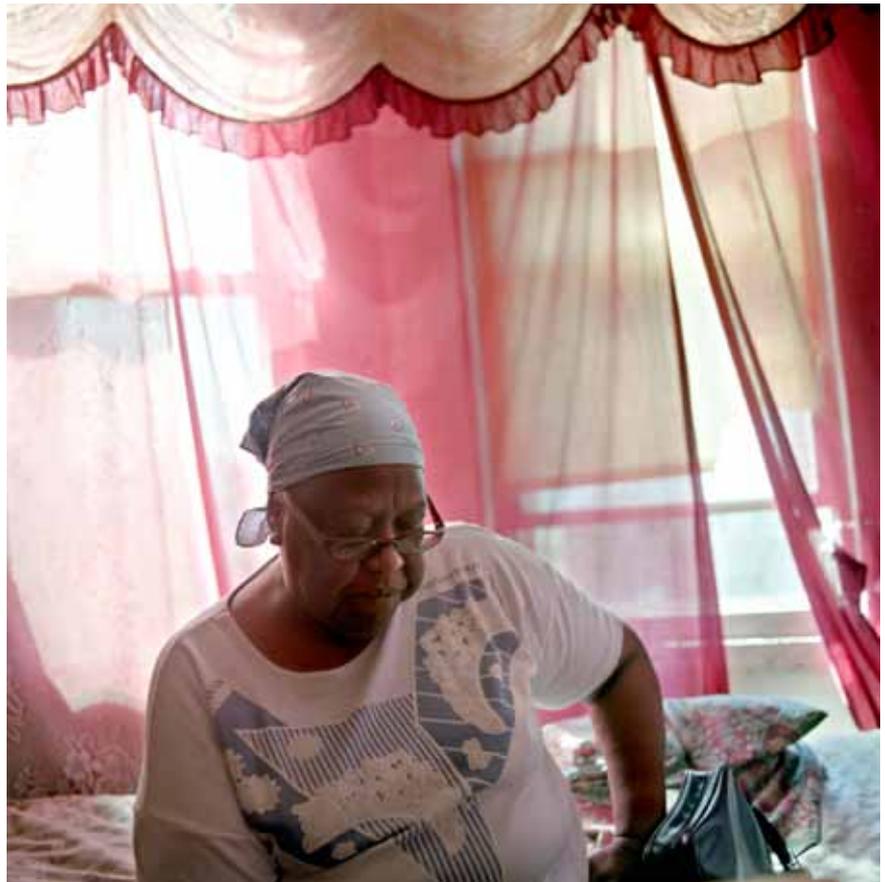
Thomas: We don't holler—we don't argue or holler. One day she was angry, she's arguing with me. So I said: "Why you got such a attitude? Why you acting like that?" She don't wanna say nothing. So I kept pursuing. And then she said, "I'm really angry because you're gonna leave me, and there's nothing I can do."

And I'm trying to take me as being a regular person, I'm in a fantasy land for a second, then I come back to reality, it's that I'm doomed, you know.

Linda: And my aunt had told me, she said, "Linda, you know it's not easy to sit back and watch somebody die." I said, "Oh, I can handle it, you know." But, it's affecting me too. I got this depression that I can't get out of.

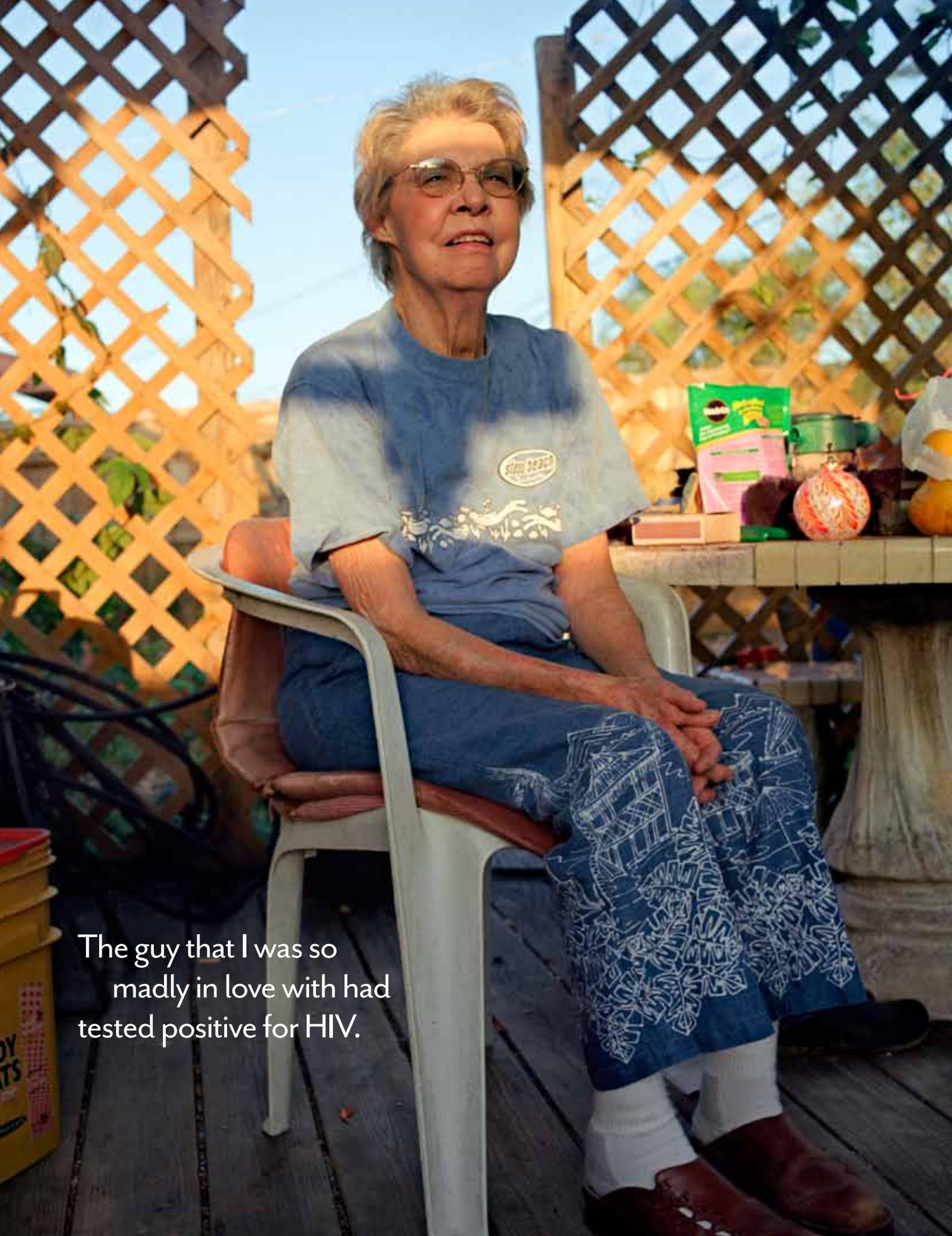
Thomas: Sometime I sit down here and I look at her and I be thinking, "What is she gonna do when I'm gone? How will she survive?" It's that she'll go through the tunnel, but I'll never make it. She's just trying to make it comfortable for me. And I appreciate that, but...

Linda: That's my job as your wife.



Thomas: Yeah, I appreciate you. Because this is a ugly death. It's like somebody, every day you wake up, somebody chopping a little piece off your body. Somebody chopping another little piece. At the end, you ain't got no more pieces left. And I'm coming to the end. And I know what's gonna happen: I have like a day dream, I have seen myself laying there in the funeral parlor.

But I can't really complain, because I had, like, 16 years. I thank God to keep me around all that time. And I got a good life, a good wife, grandkids, kids, you know, but I mean, nobody wants to die.



The guy that I was so madly in love with had tested positive for HIV.

Sue Saunders, age 73

Fort Lauderdale, Florida

THE GUY THAT I WAS SO MADLY in love with lost about 50 pounds. He couldn't go out dancing all night. We used to go fishing all day, dance all night. And he could hardly walk. I said, "What's the matter with you?" He wouldn't say anything. So the doctor called me over and he said, "Have you been tested?"

My body is old, but my mind isn't.

I said: "You're talking about AIDS!" And he said, "Yes." The guy that I was so madly in love with had tested positive for HIV.

And I said: "Why didn't you tell me?" He says, "I'm sixty-eight years old, I've never worn a condom in my life, and I'm not gonna start now."

Right after I was diagnosed, the nurse said: "How old are you?" I said, "Fifty-eight." She said, "How did you get it, through needles?" I said, "No, I got it through sex." She said: "You're having sex at your age? That's disgusting!"

They used to think that when you're 50 years old you died from the neck down. But you don't. It just gets better. So that's something to look forward to in later life.

Women who have had a happy marriage and a good sex life don't want it to disappear in their old age. And these ladies, older ladies, say: "Oh, he's so good looking, and he's so clean. And he's such a good dancer." Does she ever ask him if he's ever been tested? No.

There's not a day that you don't wake up and know you have HIV. Probably, out of nineteen years I had five good years, and those have been the most recent ones. The rest of them I've been sick as a dog. When I first started taking protease inhibitors, that was 1997. My T-cell count was fabulous, my viral load was fabulous—but I couldn't walk. Those things made me so sick! All these medicines attack everything in your body. It's just like taking rat poison every day. And you've got to do that for the rest of your entire life?

I mean if somebody told you that if you went and did this, you wouldn't have a heart attack tomorrow, you'd go and do it, wouldn't you? Or if you did this, you wouldn't have breast cancer tomorrow, you'd do it. Right,

don't you think you would? But all you have to do is wear a condom to keep from getting HIV, and that's too much to ask. Isn't that something?

You know, old people aren't old. I'm not old. I'm 73, but I don't think I'm old old. My body is old, but my mind isn't.



There's no such thing as
love if there's secrets.

Some things are better left
unsaid, but the things that are

I was raised in an era
when you didn't talk
about these things.

—Miriam Schuler, age 87, Peer Health Educator,
Senior HIV Intervention Project (SHIP)

important
must be said.

—Dee, age 57

If you ask
your mate,
what are
you saying?
Have you
been playing
around? It's
accusatory,
rather than
educational.

—Bill Rydwels, age 77

During presentations I ask “**How many of you have
been asked by your doctor about your sex life?**

Does he ask, ‘Are you safe?’ Has he ever offered you
an HIV test?” No one had their hand up.

—Paul Spearing, age 67, Peer Health
Educator, Senior HIV Intervention
Project (SHIP)

I wasn't aware of the virus. I knew about
STDs. But my baby sister looked at me one
day, she said, “Carnetta, I'd like you to come
to the health department, **I want you
to be tested.**” I said, “Tested for what?”
She said, “HIV.” I said, “What is HIV?”

—Carnetta Best, age 60

COMMUNICATING ABOUT HIV and risk behaviors related to sex or substance use can be difficult. Even when they know how to keep themselves safe, people often have a hard time talking to their partners about things like safer sex. Older adults who grew up at a time when discussion of sexuality was considered improper or vulgar can find these conversations particularly awkward. While everyone fears rejection, the stakes can be even higher for older adults who regularly struggle with feelings of social isolation and loneliness. Older people living with HIV appear to be particularly vulnerable: 71% of ROAH respondents aged 50 and older lived alone, as compared to 35% of their HIV-negative peers aged 65 and older.⁷

Especially for seniors, it's a rough time simply because they have few family and friends left—they don't want to lose them. So they're afraid to identify themselves as HIV-positive people. —Bill Rydwels, age 77

Who's gonna be there for you? You still need people that you can share certain things with and feel comfortable. All those things are fairly common for everyone, whether you're gay or straight... —Larry McKeon, age 61

Open communication with loved ones about health concerns can play an important role in staying healthy, but some older adults may find it difficult to discuss their sexuality or HIV status with family members, especially their children.

Seniors don't want their kids to find out that they're having sex, and so they will avoid going to the doctor because their daughter drives them, goes in with them because they're hard of hearing... They don't want to have this conversation. And the older you get, the more likely you are to have a physician who is probably significantly younger than you are, talking to someone who seems like his grandmother about sexual issues. It just doesn't happen.

—Jeanine Reilly, Nursing Home Administrator

Patients and their health care providers can find it difficult to discuss sexual behaviors, substance use, and HIV for a variety of reasons. Providers may make assumptions about their patients' sexual orientation, gender identification, or risk behaviors, and their patients may not feel comfortable correcting them. HIV testing guidelines differ from state to state, with some states still requiring a separate informed consent in writing before an HIV test will be administered. Many older adults may assume that they will automatically be tested for the virus when their blood is drawn or may feel uncomfortable asking for the test, and some providers may feel awkward initiating this discussion with their older patients. Linguistic and cultural barriers can make these discussions even more difficult.

There was, like, one section in one chapter about sexuality and the elderly. Not really how to ask an 80 year old... anything. —Male nursing student, age 25

I went to the doctor for regular checkups and blood work, and I was called back because something was not right. There was a problem, because I didn't speak English. We had many problems finding an interpreter to explain things, who could help us. —Apolonia, age 66

Finally, the way providers communicate with their patients can have a huge impact on the patients' mental and physical health.

Sometimes I think you get the attitude, "What the hell? You're 60, you're 65, you're 70, you're gonna die anyway, so why should we worry?" —Larry McKeon, age 61

The last time I had a cancer the doctor thought maybe the treatments weren't working and she said to me, "Bill, have you got everything prepared?" And I thought, "Oh my God, what are you saying?" And I went home depressed and she called me, she says, "Well, Bill, we're not saying you're going to die. Let us do one more test." —Bill Rydwels, age 77

Carnetta Best, age 60

Fort Lauderdale, Florida

I WOULD LIKE TO SAY THAT it's not the end. There was a time when somebody said you had HIV, you felt like you were doomed. But they have come so far in our society with this disease that people are living much longer. I tell you, I couldn't feel better. I'm 60, and I've had it since '91.

I got tested, I was told to come in for my results, and it felt like everything in me just hit the floor. Because I really didn't know

nothing about it. I started very desperately preparing for my death. But every day that I live, God let me become more and more aware. There are things that can be done. It took me a while, but I stuck with it. I can tell you my viral load, I can name all my medications. These things we have

**Don't be afraid
to discuss what you're
going through.**

to do on our own. We can't expect doctors and social workers to stay on top of things for us. You got to take some responsibility yourself.

Don't be afraid to discuss what you're going through. Get involved in different programs, and do whatever you can, whenever you can, to help you to do better with your life. It has been a great help to me, and I don't mind passing the word along. I talk to people. I try to inspire them that they are the most important person.

A lot of people feel guilty. Some people have such terrible guilt. The thing we need to know is, it's not your fault. It's all kind of ways of getting it—your husband can give it to you. Wives can give it to you. It's what you're gonna do now that you have it. It's not a death sentence. But at the same time, you will have to change your lifestyle. Are you gonna continue to live, or just dig the hole and fall on in?



Ronald Johnson, age 58

Washington, DC

CERTAINLY, SINCE THE ADVENT OF PROTEASE INHIBITORS and the real progress in antiretroviral medication, the ability to treat HIV infection and slow down the progression to serious illness and death is very real. However, the disparity in being able to reap the benefits to the treatment advances is also very real in the United States, and certainly when one looks at the global epidemic. Health care is still very much a privilege and not a right, so a person's socio-economic status affects the degree to which he or she has access to the medications. There are racial disparities in health care which make the ability to take advantage of the medications an issue of race. So, the disparities that we have in our society continue to play out in the AIDS epidemic.

I learned of my HIV infection in October of '89 and enjoyed an asymptomatic period until 2 years ago. How and why I got sick is a mystery to both my doctor and I, but the fact is that I contracted PCP. That's the definition of AIDS, so I moved from being asymptomatic HIV-positive to AIDS. And that also meant that I needed to start taking medications. Taking the drugs represented a sort of a Rubicon of illness that frightened me. I guess it was easier than

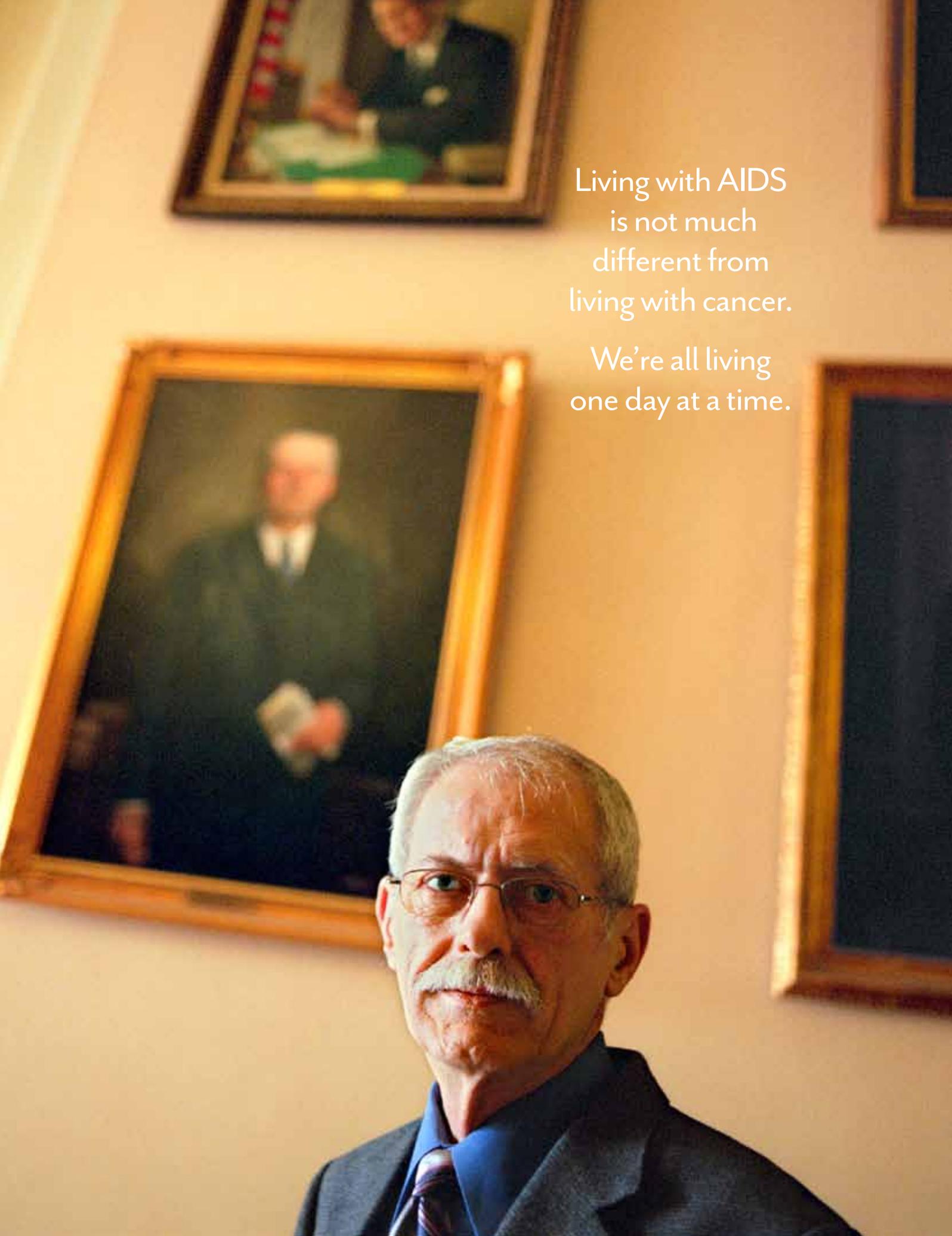
The disparities that we have in our society continue to play out in the AIDS epidemic.

I thought it would be. We always project a catastrophe, and when the reality comes around, it's often not as bad as we thought it would be. I was very fearful that I would miss my regimen's schedule, and with ARV, you have to adhere to the schedule. I'm amazed at myself at how disciplined I've been at taking my medications.

I've been in a committed monogamous relationship for 5 years. My partner, who had AIDS, died in '95. After the death of my partner I was getting back into the dating world after a relationship of 11 years. One of the things that shocked me was the degree to which safer sex was not necessarily a given. More often than not I had to bring up the issue, and that kind of surprised me, that things could easily have progressed without the issue coming up.

People are living longer. I just assumed that I would be dead by the time I was 50. I'm 58. So geriatric care and HIV care are going to have to be more blended. It's going to be an increasing population, but we have to look at the issues. How is HIV going to increasingly affect Medicare? When more and more people who are HIV-positive are eligible? And as people get older that's going to be more and more of a burden.





Living with AIDS
is not much
different from
living with cancer.

We're all living
one day at a time.

Larry McKeon, age 61

Illinois House of Representatives
Springfield, Illinois

If you're not in a relationship, who's gonna take care of you?

I WANTED TO DO something that made a difference, and that's why I took the job for Mayor Daley as his representative to the gay and lesbian community. A spokesman for one of the radical groups said I was too old to represent gays and lesbians. You have this ageism in the community—it's so youth-oriented, you don't feel welcome. As if you turn 40 and you turn straight or something. I can assure you that didn't happen.

I ran for office, which was pretty grueling. There wasn't a closet big enough for me to go back into. The big issue in terms of my supporters was that this would be the first time an openly gay man ran for state office. But the local newspaper comes up and says: "Well, I understand you're HIV positive." Some of my supporters took a walk: "Bad enough you're queer, but now you got AIDS."

But I had people who I didn't even know—heterosexuals who were survivors of breast cancer, or prostate cancer, or cervical cancer—slap me on the back, you know, "Atta boy!" I always told people: living with AIDS is not much different from living with cancer. We're all living one day at a time.

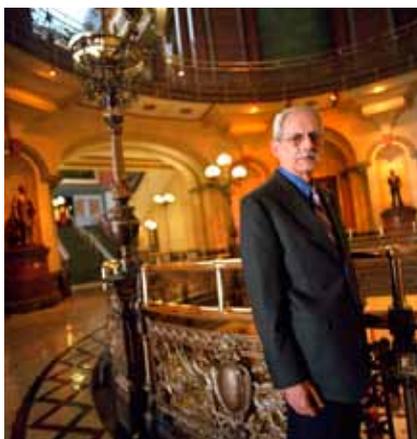
I think as we age we sort of simplify things a lot, but it takes a few years, 30, 40, 50 years to figure that out. You have different priorities, different needs. If you're not in a relationship, who's gonna take care of you? When I was struggling with

cancer, there were 15, 20 people taking off work, taking me to radiation therapy, helping me clean my apartment, going grocery shopping.

I stopped taking my HIV meds while I was going through chemo. I had a tough time getting back onto my regimen. Right now none of my drugs work, so I'm gonna be making some major changes. And then you go through 2 or 3 months of the severe side effects, and that'll settle down as the body acclimates itself.

There are certain diseases from heart disease to prostate cancer to other cancers that manifest themselves as you move from middle age to maturity. It becomes a real issue of outreach—getting service providers to recognize there are people in their 50s, 60s and 70s that are struggling with HIV. You gotta be very careful what you prescribe because of interaction effects and so forth. You need chemo docs, radiation docs that understand the complications that HIV brings to the table. They need to have some access to someone who says: "No, you can't give him that drug."

It's been about 20 years since I've known I was HIV-positive, so I'm considered a long-term survivor. In many ways it's a transformation, a conversion kind of experience. How have I lived my life? It's not necessarily about material things, it's just: "Have I made a difference?" And I think that's what a lot of us think about when we get into maturity: "Did my life contribute anything?"



Stigma

DEALING WITH ANY ILLNESS can be difficult, but the stigma associated with certain diseases can add additional hardship in the form of judgment and social exclusion. Some illnesses are more heavily stigmatized than others; HIV/AIDS has been particularly stigmatized since the beginning of the epidemic.

We made tremendous progress, but we still have a ways to go, and since we're dealing with such bedrock values and issues around sexuality, sexual activity, drug use, it's going to be slow to change some of the remaining amounts of the value issues that lead to stigma. —Ronald Johnson, age 58

I used to say, "I'm a person with AIDS," and people would back off. —Richard Kearns, age 58, activist and blogger

Additionally, ignorance about how HIV is spread can lead friends, family, and community members to avoid physical and social contact with people who are HIV-positive. Despite fears to the contrary, HIV is not transmitted through casual contact like hugging, shaking hands, or sharing a meal with a person with HIV.

When I went to my support groups, some people would talk about their family, how they rejected them, or when they go

to their houses they give them plastic plates and knives and forks, and I said to myself, if I need to go through that I'm gonna find out right now. So I told my brothers and my sisters, and I told my mom, and to my surprise, I didn't feel that rejection. I guess I was lucky.

—Louis Curbelo, age 51

So the elevator opens up and it says "Department of AIDS Services." A bunch of us got on. Don't you know that all them people that was on the elevator squeezed to one side. So one girl says, "I should blow on 'em!"

—Thomas Jones, age 58

At times, these negative messages can be internalized by people who are living with the virus, resulting in feelings of shame, a decreased sense of self worth, and difficulty reaching out to others for much needed social support. Fear of rejection can lead some to keep their diagnosis to themselves, increasing their sense of isolation. More than half of the HIV-positive people aged 50–65 interviewed for a 2006 study acknowledged practicing “protective silence,” not telling others about their HIV status as a way of managing their fear of HIV-related stigma.⁸

A lot of people don't tell you. I guess they're ashamed. You know, maybe embarrassed that they succumbed to this. Because it has a lot to do with sex, drugs, so they would be associated with both those things. —Dee, age 57

Until we accept sex as a natural, wonderful experience in life that everybody should have, we're accusatory. If you have an STD, a sexually transmitted disease, you're a dirty person. You've done something wrong. —Bill Rydwels, age 77

Social stigmatization can take many forms. While people of all ages living with HIV may experience HIV-related stigma, older adults living with the virus may also feel marginalized by ageism in American culture in general and by youth-obsessed segments of the gay community in particular. “Ageism” describes a cluster of negative attitudes about older people, including that they are less sexual, less appealing, and less competent. A 2006 study of older adults with HIV/AIDS found that 68% (all but those in their early 50s) experienced both ageism and HIV-related stigma.⁹

You don't feel welcome. When I was 50 or 51, there was comments by some folks that I was too old to represent the gay and lesbian community. As if you turn 40, and you turn straight or something, you know what I mean? I can assure you that didn't happen. —Larry McKeon, age 61

Health care and social service providers—like everyone else—sometimes make assumptions about people based on personal prejudices that they may not be aware of. Ageism and HIV-related stigma—as well

as racism, sexism, and homophobia—can impact relationships between older people and their care providers. Problematic behaviors can include overt discrimination, “infantilizing elderspeak,”¹⁰ violation of patient confidentiality, and exclusion of patients from provider/family discussions of patient care, regardless of a patient’s cognitive abilities.¹¹

When we first started getting HIV patients it would be like, “Oh my gosh! So and so is HIV-positive!” Everybody felt like they were seeing the boogie man. I think those sort of attitudes are changing now. We need more nurses, doctors, therapists, to know about HIV and to realize that they are just regular people. —Petra, Physical Therapist

Sending people with HIV to a traditional nursing home has its own challenges – for the resident and for the nursing home. There's the roommate and their family saying: “I don't want them using my toilet, I don't want to share a bathroom – that's very intimate.” And people are really afraid. —Jeanine Reilly, Nursing Home Administrator

When people first found out that I had HIV, nobody would call me, nobody would talk to me. Nobody would touch me. You can have cancer, you can have multiple sclerosis, you can have bird flu. And that's acceptable. But HIV is not acceptable. In any way. —Sue Saunders, age 73

It's not the fear of dying—we're all going to die. **It's the fear of being rejected.** But thanks to God, I am surrounded by many great people, my case manager, and those in my family who know support me. —Apolonia, age 66

Dee, age 57

Broadway House for Continuing Care
Newark, New Jersey

I DON'T FEEL OLD. I never thought of myself as being 57, 60. I didn't think that far, you know. I feel young at heart. I like to have fun. I don't know, just being happy.

They didn't expect me to pull through. I was really sick. They gave me last rites. But I survived. And here I am... Which I'm glad.

I don't know the exact date that I got it, but I would say about 20 years ago. I think I got it from my husband. I'm pretty sure, pretty sure.

He dropped me off, 'cause I was sick, and they kept me. He came the first three days that I was here. I haven't seen him since then. I guess he got scared.

I don't know if he's doing too well right now, I think he is doing drugs, from what I hear. That's one thing I'll never go back to. I don't want no part of it. I wish him luck, it's all I can do.

I was married twice. If I had to do it over again, I would have children. But maybe it was God's way, being that I'm sick, children didn't come into my



**I always said to myself:
I wonder if I'm gonna get sick.**

life. I have my nieces and nephew. I don't see them very often. But I can understand them not wanting to bring the kids here, you know. Although I would like to see them.

I was born in Belleville. It's a "town" town—has one high school, everybody knows each other... nice. It's a good place to grow up. I was pretty good in school. I was a cheerleader, I think. I didn't go to college. Financially, it was hard for my parents at that time. I was a book keeper's secretary. I liked working.

When I started getting sick, I went on disability, and everything happened from there. I lost a lot of things when I was unconscious—a lot of paperwork, most of my clothes, all my jewelry. Everything I lost. It's gone. It's gone.



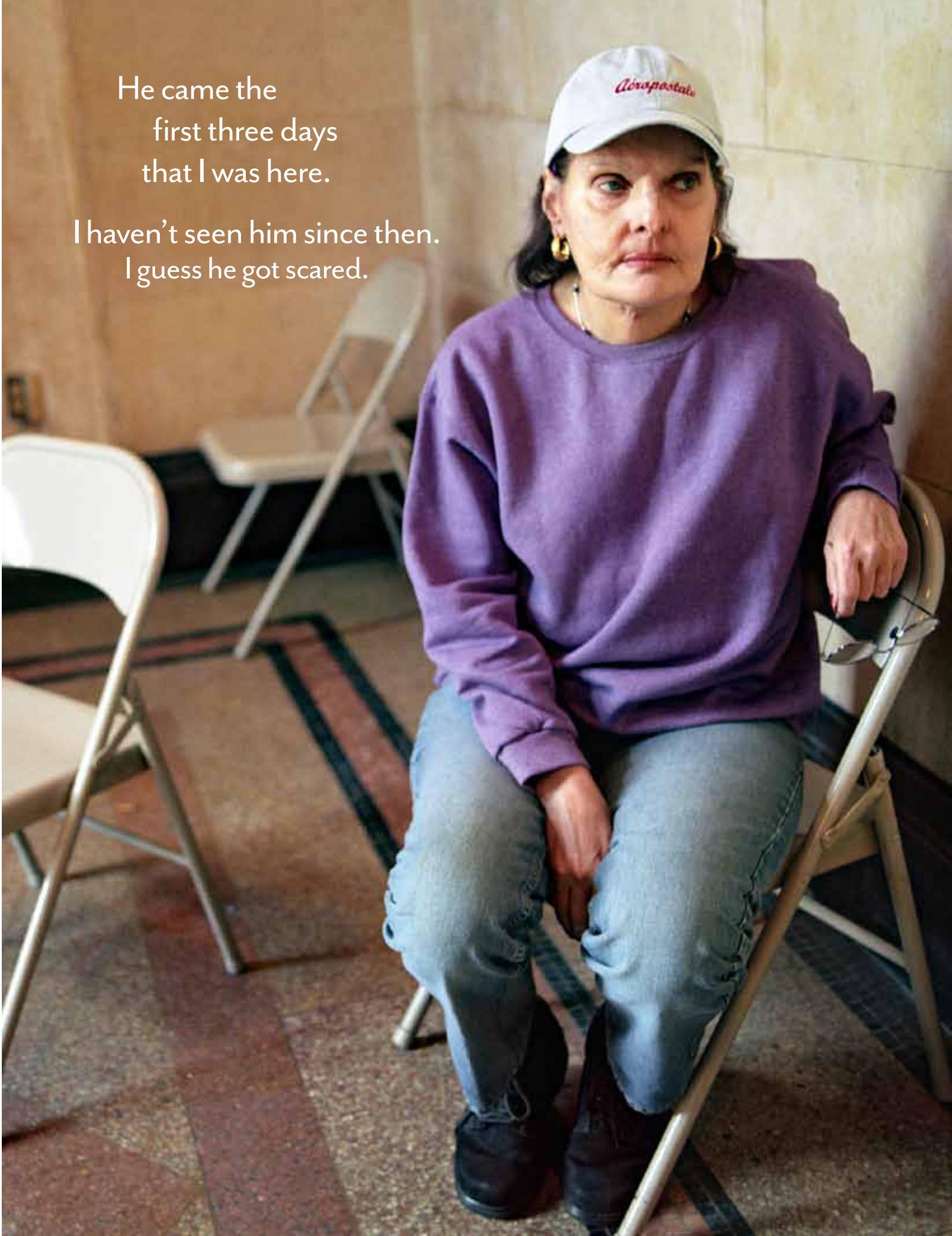
I'm glad I came here. I'm happy right now. They don't look down at you here, they treat you like a human being. It's a nice place.

I really didn't think I'd live this long, you know. I wasn't seeing anyone for the virus, I was just taking it day by day. And I always said to myself: I wonder if I'm gonna get sick. And sure enough the day came. I guess I didn't want to deal with it, you know what I mean? But reality struck.

It's amazing, the things that I have forgotten. But thank God, I'm hopefully back to normal. I was much worse, boy, I couldn't walk, I was in a wheelchair. So, I've come a long way. I knew so many people who have died. So sad. I thank God I'm still alive, really.

He came the
first three days
that I was here.

I haven't seen him since then.
I guess he got scared.



How It Feels

The Physical and Mental Realities of Living with HIV

MANY DISEASES AND INFECTIONS affect a specific part of the body, but HIV lives in the immune system and therefore ultimately impacts the whole body. While health care providers are trained to be experts in highly focused areas within the mental and physical health fields, they need to be sensitive to how the lines between their specialties can blur and work closely with other providers to maximize benefits for patients. Coordinating care is critical, as many medications can become dangerous or ineffective when combined. Side effects for medicines addressing physical ailments can include mental health issues like depression, and medications addressing mental health conditions such as depression may include physical symptoms like nausea or fluctuations in weight.

Similarly, some of the challenges facing people living with HIV can be understood as both physical and mental health conditions. Dementia impacts both the way the brain processes

I've got neuropathy in my hands and my feet. If

you touch something that's hot, it's like fire. And if you touch cold, that feels like fire. But if you do touch anything, it's just—like electricity. And it's the same way with your feet. A lot of people are up all night, walking around in agony from this. The pain is just excruciating. Mine hasn't gotten that bad yet. Hopefully it never will. —Sue Saunders, age 73

information and peoples' emotional lives. Diarrhea can be a side-effect of some HIV medications; it can also have a profound impact on how people feel about themselves and their ability to leave the house. Some people struggling with the emotional fallout of their HIV diagnosis may seek comfort in alcohol or drugs; in addition to the usual strains these substances can put on their organs, substance use can impact their ability to keep up with their medication and other self-care regimens.

Physical Issues

There's still a lot we don't know about HIV/AIDS, especially when it comes to aging with the virus, but some things we do know. HIV affects the body's immune system: without proper treatment it becomes harder and harder for a person with HIV to fight off infections and diseases over time. Some of these illnesses, known as "opportunistic infections," are considered "AIDS defining"—when an HIV-positive person develops one of these infections or diseases, their diagnosis shifts to "AIDS."

My viral load is undetectable, my CD4 count is at a good range, and my health is good, knock wood. And I've had no major side effects to the drugs. So I realize that I've been very lucky. And I have not had to change my drug regimen since I started. —Ronald Johnson, age 58

HIV affects everyone differently—some people live with the virus for a long time without getting sick, while others experience problems more quickly. Many people with HIV don't realize they have the virus and may approach their doctor with complaints that sound like normal symptoms of aging. If their risk behaviors don't come up in conversation with their doctor and they don't get tested for HIV, they may not be diagnosed until a later, more advanced stage of disease.

Most people only get kind of a cold, or flu symptoms, but I had this horrible sore throat. My doctor said, "You have a horrible virus, your thyroid is doing summersaults. I don't know what you have." Never thought to test me for HIV. A 58-year-old white woman, she doesn't have sex, right?

—Sue Saunders, age 73

There is still no cure for HIV or AIDS, but studies show that the sooner people get into treatment the better. But people can face a range of obstacles to accessing care, including living far away from experienced HIV providers, depending on inconsistent or inadequate public transportation systems, lacking health insurance, and confronting social barriers related to race, class, ageism, cultural differences, and homophobia.

For those who start on medications, the options available today are much better than what used to be available, but the side effects can be difficult for some people to tolerate.

I get around somebody that got a cold, I wind up with pneumonia. It's just like you being a baby, you have no resistance. I wanted to go see my grandkids, but they had a stomach virus, I was petrified, I couldn't go up there.

—Thomas Jones, age 58

I had weight loss syndrome, I had night sweats where I had to wake up about 7 or 8 times drenched wet. I had the mood swings. Sometimes I couldn't hold food real good, because it gave me nausea and I'd bring it back up.

Those are the side effects. —Louis Curbelo, age 51

The medicine that they had me on, it was just making me so sick. Oh, it was like I just don't wanna live if I have to live like this. But they said the medicine that will help you makes you sick at first, until you get used to it. But it took a long time for me to get used to it.

—Jackie Anderson, age 54

In addition, older people with HIV are more likely to experience "co-morbidities" like heart, kidney, and liver diseases, neuropathy, arthritis, and some cancers. The virus may also speed up the aging process, even among people with seemingly well-controlled HIV, including an "undetectable viral load": some men and women with HIV in their 50s experience problems that normally develop much later in life, like osteoporosis (particularly unexpected in men), certain cancers, diabetes, and dementia. Some of the medicines patients take to address these illnesses cannot be combined with certain HIV medications, making treatment even more challenging.

You have to read up on every single medicine, what it may do to you, what the side effects may be, what you can't mix it with. I can't take things like Celebrex—I have severe arthritis, I can't take any of those medications, because of the medicine I'm taking. And if you take it together, you just get sicker. So you have to know what you're doing, and it's not easy.

—Sue Saunders, age 73

A support group can give you: hey, you're having a bad day today. Meet me and I'll take you out, we'll go and do something. They can help you out of your doldrums. We're all gonna have 'em.

You can talk your problems through. —Bill Rydwels, age 77

Some studies suggest that women living with HIV may go through menopause at younger ages than their HIV-negative peers and may experience more menopausal symptoms like hot flashes, decreased bone density, and increased heart health risks.¹²

On a day-to-day level, having a compromised immune system means that people with HIV are extremely vulnerable to germs that other people—including the people who care for them—are able to fight off far more easily.

I have seen people not really understanding what immunosuppression is and coming to work sick. It's a deadly consequence to come into work. That's common sense, but it's really important information. Especially people that are lower socio-economic group, that really need their money. They really struggle with that decision sometimes.
—Laura, Psychiatric Nurse Practitioner

Mental Health Issues

People with mental health and substance use issues are less likely to practice safer sex and drug use behaviors, which increases their risk of becoming HIV-positive; they are also more likely to learn about their infection later in the disease process. Once diagnosed, people with these issues tend to start treatment later and can have a harder time following up with their providers and consistently adhering to the structured treatment schedules associated with many HIV medications. What's more, stress, depression, and substance abuse have all been shown to lead to decreased CD4 counts and a faster progression to an AIDS diagnosis.¹³

My own experience of dealing with depression and anxiety really came out after I got sober. So probably I had those issues for a long time, but I was self-medicating with alcohol. And that really became apparent when Ray died. I had a tough year.
—Larry McKeon, age 61

I wasn't taking medicine for about two years, 'cause I was still into the drug use. So the medicine I was getting, I was selling it, you understand. And each day go past, I was getting worse and worse. —Thomas Jones, age 58

I came to decide that I was not gonna let the HIV/AIDS kill me, I was maybe let the drugs and the alcohol do that. Because I seen too many people go like that, wasting away, like vegetables. And I wanted to make my own choice of how I wanted to go. —Louis Curbelo, age 51

Depression and feelings of isolation are common among older adults living with HIV: the ROAH study¹⁴ found that they experience depression at a rate almost 5 times higher than the general New York City population. Physical challenges like chronic pain and practical challenges like accessing appropriate housing and expensive medications can contribute to the problem. A changing sense of self and the loss of independence can also be extremely difficult.

I can't do nothing, and it bothers me 'cause I'm so used to doing things by myself. Now I got other people doing things for me. I don't like it but ain't nothing I can do. Ain't nothing I can do. —Thomas Jones, age 58

I had lost weight. I was in a deep depression. And then after that, one of the CNAs (Certified Nursing Assistants) threw my teeth away. It took a toll on me... after I lost those, I started going downhill. I was crying a lot.

—Jackie Anderson, age 54

It can be incredibly challenging to navigate the emotional roller coaster that can come with an HIV or AIDS diagnosis, and the coping strategies that work well for some people might not be right for others. Support groups can play a central role in improving a person's quality of life. While individual therapy can be extremely helpful for some people, it is not for everyone.

Support groups are marvelous. The world is filled with beautiful people who are gonna help you stay healthy. Most of my family is dead by now and I needed family. My family is my community of gay people and they have been wonderful, not that heterosexuals haven't been grand to me either.

—Bill Rydwels, age 77

Therapy, I don't even wanna see that word no more. They therapy you to death. —Thomas Jones, age 58

Others find comfort in spirituality, which can have a positive impact on their physical health as well: one study found significant increases in spirituality after HIV diagnosis, which it also linked to better CD4 counts.¹⁵ While some may find it surprising, an HIV diagnosis—and the subsequent efforts to make sense of what it means—has inspired many people to make positive life changes.

I might have called it prayer, but now I call it meditation. It's still spiritual. And it certainly was the mainstay in my time of illness. —Robert Brewster, 74

It's funny that it took the HIV to change my life to a positive, because through the drugs and the alcohol, I don't know if I'd be sitting here today. It keeps me humble to be here.

—Louis Curbelo, age 51

We're all living one day at a time. It's in many ways a humbling experience. In many ways it was a blessing. **You learn to cope** with

I have AIDS-related dementia, which is a pretty frightening prospect for somebody who lives by the mind. But it only means I have trouble remembering numbers so far, I have trouble remembering names, I get times mixed up, I have to have a nurse come in and give me shots. But I know the important stuff. I haven't lost my mind. I know what the truth is and I speak it.

—Richard Kearns, age 58, activist and blogger

grieving, death, grieving the loss of your health, but at the same time in terms of my personal experience, I ended up over time renewing my relationship with my higher power.

—Larry McKeon, age 61

Now it is about living for *me*.

It is about happiness.

It is about trying to experience as much of life's beauty that I can experience in the next... in the rest of my life.



Robert Brewster, age 74

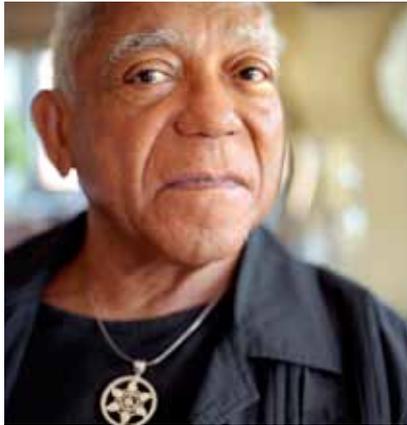
New York City, New York

I WAS ALWAYS WORKING on my music. That was a part of who I was. I was practicing instead of going out to play baseball or do sports. That was in Birmingham, Alabama. And I left Birmingham when I was sixteen. Graduated Wheaton College with a Bachelors of Music degree and in piano. I finished the PhD and went off to Germany as a Fulbright scholar and stayed in Germany for 18 years. Where I performed, taught. I had my first engagement in the Wiener Volksoper and Kammeroper in Vienna.

I suppose that my living in Europe allowed me to really become aware and accepting of my status as not just a heterosexual but as a bisexual. And that was, of course, after marriage, after a son... and then divorcing.

The chorale was my last attempt at anything professional. It really was an incredible and exciting time, making a difference in the lives of others, as well as in my own life. To inspire men who had the virus and give them an outlet for their talents. And I think it also helped in the healing and the well-being of each individual.

And the sound was just incredible—mature voices, and they were all spirituals. It was so emotional and inspirational... But we didn't get very far. I had to actually disband the chorale because I had become ill. Again... One illness after



the other. One bout with this or that. Cancer, skin cancer, pneumonia... It has ruined my life for the last 15 years.

I lived more than a year and a half with measurable two T-cells. I heard all from 'he has another year,' 'he has another month,' 'if he lives this month out, he'll be lucky'... But today I feel like, that is certainly not the case any longer. And even if I were to die tomorrow or the next day, I don't have that sense of doom and destiny.

I really learned about my body. Not only scientifically, but also being able to listen to your body. I think meditation is a part of how I keep my center. With all the pills and all the drugs and all the radiation and all the stuff that I've gone through, I've always used a certain amount of alternative aides that were not a part of the normal HIV routine. I think that's one of the real main reasons that I'm still alive today. Fifteen years later. Somewhat healthy, which is pretty cool. I have more energy... and bouncy, and perky, and running and ripping, and doing things I have not been able to do for a very long time.



Now it is about living for me. It is about happiness. It is about trying to experience as much of life's beauty that I can experience in the next... in the rest of my life. It would be also about companionship, about sharing with someone. And I believe it will happen. I'm at that crossroads at the moment. And it's a beautiful time in my life.

30 Years of HIV/AIDS and Counting

The Graying of AIDS in Context

THE HISTORY OF the HIV/AIDS epidemic can be broken down into the periods before and after 1996, when modern HIV treatment, known as “highly active antiretroviral therapy,” first came into widespread use. The individuals profiled in *The Graying of AIDS* were diagnosed as HIV-positive before effective combinations of medications had been developed, and their experiences with the virus reflect the harrowing early years of the epidemic. Living with HIV and AIDS today is still a challenge, but we have come a long way in a short period of time. It is important to recognize the critical breakthroughs that have resulted from the tremendous commitment of time, energy, and resources by providers, activists, researchers, and funders; the extraordinary

obstacles long-term survivors have overcome; and the important work still ahead of us.

In June 1981, The Centers for Disease Control and Prevention (CDC) first reported clusters of unusual illnesses among gay men in major American cities. This outbreak, initially dubbed “Gay-Related Immune Deficiency” (“GRID”) was re-labeled “Acquired Immunodeficiency Syndrome” (“AIDS”) in 1982 when it became clear that the illness was not confined to the gay population. In 1984, researchers identified the virus that causes AIDS, which was eventually named “Human Immunodeficiency Virus” (“HIV”).

It took a few years to develop treatments that could keep HIV in check. In addition to being extraordinarily expensive, early HIV medications like AZT were often prescribed in high doses to be taken every four to six hours. Though such medication schedules could be difficult to adhere to, strict observance was critical to ensure treatments remained effective. The few drugs that were available were often highly toxic, difficult to

tolerate, and increasingly ineffective over time as the virus was prone to develop “treatment resistance” to drugs that, in those days, tended to be prescribed individually rather than in combination.

In the mid-1990s, the development of different kinds of antiretroviral medications (“ARV”)—each interrupting a different stage of virus replication—and the practice of using three or more of these medications at the same time brought new hope to people living with the virus. This treatment approach—often referred to as “HAART”—meant that even if the virus stopped responding to an individual medication in the “cocktail,” the other medications could effectively suppress the virus while new drugs were being developed. Early HAART regimens still required taking multiple pills at strategically timed, round-the-clock intervals. However, as treatments have continued to evolve, medication regimens have become much simpler, although challenges related to long-term toxicity, tolerability, and compatibility with other medications remain.

Treatment results, while often remarkable, vary from person to person for a number of reasons including the stage of HIV disease at initial diagnosis, other illnesses or medications that might impact a person's ability to tolerate treatment, and drug-resistance that builds up over time. And despite the best efforts of critical programs like ADAP (AIDS Drug Assistance Program) that help bring essential medications to people who can't afford them, the inconsistent access to high quality health care from community to community and region to region has meant that many living with the virus have been unable to take full advantage of the extraordinary advances in treatment made in the last fifteen years.

If there is a downside to these treatment breakthroughs, it is that they have made it easy to become complacent. A shared sense of urgency has, for some, given way to a mentality that with all of these great new medications available, HIV infection "isn't that big a deal" anymore; at the same time, many continue to cling to the idea that HIV infection happens to "the

other guy." The truth is, of course, a bit more complex than that: while it *is* possible to live much longer and more comfortably with HIV these days, HIV infection is *not curable* and requires *life-long* treatment. What's more, both the virus and the medications used to treat it can

People with AIDS made the original connection between AIDS and aging on the internet. We talked about our osteoporosis. We talked about our dementia. We have more cancer. We have high blood pressure. We talked about all the things that go wrong and we went **"Hey, this is like getting old. But I'm too young to get old."** No, I'm not. Nobody's too young to get old.

—Richard Kearns, age 58, activist and blogger

wreak havoc on a person's body over time. And while anyone *can* become infected with the virus, it *does* disproportionately impact some groups (for example, "MSM" or "men who have sex with men," and African Americans) more than others. What's more, in the autumn of 2008 the CDC published the first set of statistics created using an improved methodology and

found that earlier methods had underestimated the rates of new HIV infections for many years. We now know that new infections in the US have remained relatively constant since the late 1990s, although the demographics have shifted over the course of the epidemic.¹⁶

At the same time, many long-term survivors are struggling with the consequences of this societal complacency. They find themselves without key sources of emotional and practical support as peers have succumbed to AIDS or, as with many older adults, they have lost loved ones to aging-related illnesses or relocation. Burdened with heavy case loads and insufficient resources,

case workers do their best to help support their clients, but can't really fill the shoes of the loved ones who so often act as health care advocates and provide much-needed day-to-day caregiving. All of us need to step in and do a little more.

The need to support those aging with HIV is not just a moral imperative: it is an opportunity for us to learn. Most HIV/AIDS research to date has focused on younger people and has excluded older individuals who are often living with multiple serious illnesses—which can include heart, kidney, liver, and bone disease, as well as dementia—leaving many questions about the simultaneous management of HIV and aging-related issues unanswered. Even when people respond well to the HAART medications, AIDS appears to accelerate the aging process, so that some people in their 50s living with HIV infection can experience illnesses we might not normally see in a person until their 70s or 80s.

We already know that the aging of the baby-boomer generation will put unprecedented strain on our health care infrastructure; the aging of AIDS will only compound these challenges. By working with

I only take one pill a day for my HIV,
the rest are for all my aging issues.
And it's great that I've lived to be able
to take aging issue drugs! It's a blessing...

—Bill Rydwels, age 77

older people with HIV we can provide much needed support today while gleaning critical insights for tomorrow.

In the coming years, we must expand clinical research to learn how medications used to treat HIV are or are not compatible with medications used to treat age-related illnesses and understand what the long-term effects of HIV medications—both on their own and in combination with other medications—might be. We must prepare our providers and medical and social service institutions for the wave that is coming, sensitizing gerontological specialists to HIV issues and HIV specialists to gerontological concerns. We must build interdisciplinary collaborations and expand approaches to coordinating care for older adults living with an array of health concerns. When people are no longer able to live independently, we will need assisted living and nursing care facilities that are adequately trained, staffed, and

equipped to support older people with AIDS. As many LGBT (lesbian, gay, bisexual and transgendered) elders can attest, a lack of awareness and sensitivity around issues of sexuality and sexual orientation on the part of both staff and residents can have significant psychological and physiological consequences. What will happen when HIV is increasingly added to the mix?

Throughout the history of the epidemic, patient activists have played a critical role in identifying key issues and pushing through obstacles to quality care. Providers and policy makers need to encourage continued engagement of patients, their families, and their communities as we tackle these new challenges: the graying of AIDS demands collaboration and partnership not just between different medical and social service specialists, but also with patients themselves.



Glossary

Important Terminology Used in *The Graying of AIDS*

AIDS

Short for “acquired immune deficiency syndrome,” the life-threatening stage of HIV infection. A medical diagnosis for people whose immune systems are so damaged that either (a) their CD4 count drops below 200, or (b) they develop one or more *opportunistic infections* or cancers known as *AIDS-Defining Conditions (ADCs)*.

Antibody

Proteins tailored by the immune system to attack specific antigens (unwelcome elements like viruses) introduced into the body. Most tests used to look for HIV infection look for HIV antibodies in blood or oral fluid (different from saliva). Most peoples’ bodies produce enough antibodies to show up on an HIV test within 3 months of infection, although it can take longer for some. During this window period—which can last from 2 weeks to 6 months—a person can infect others, whether or not their test indicates that they are positive.

ARV

Short for “antiretroviral therapy.” HIV, a retrovirus, inserts its genetic code into the cells it invades, which then act like tiny copy machines, helping the virus replicate. Retroviruses cannot be cured, but each of the seven different classes of ARV medications available (including *protease inhibitors*) interferes in some way with the “copying” process; in the US they are usually prescribed in combination. It is important not to skip doses of these medicines if they are to remain effective and prevent the virus from mutating into a drug

resistant strain. (See also “HAART/Combination Therapy.”)

Asymptomatic

Regardless of what tests may show is going on inside the body, the person is feeling fine and not experiencing any symptoms from their infection. This does not mean the virus is gone, but rather that it is affecting the body in ways that are not noticeable to the patient.

CD4 cell/T-cell

A type of white blood cell that, in a healthy immune system, attacks and defeats germs that can cause illness. HIV reduces the number of these cells in the body, allowing illnesses to take hold. A high CD4 count is good because it means the body has more of these cells to fight infections and cancers. If an HIV-positive person’s CD4 count drops below 200, their diagnosis shifts to AIDS, whether or not their CD4 count goes back up again later.

Co-infection/Co-morbidities

Having more than one ailment at any given time (like HIV/AIDS and Hepatitis or HIV/AIDS and Heart Disease).

Cross-infection/ Reinfection/Superinfection

Infection with more than one version, or *strain*, of HIV.

Dementia

Physical changes in the brain that can affect aspects of a person’s ability to function (including memory, speech, and basic motor functions) as well as their personality (including mood, behavior, and judgment). Older people with HIV may display symptoms of dementia if they: (1)

develop *AIDS-Related Dementia (or HIV encephalopathy)*, an AIDS-defining condition associated with later-stage infection; (2) develop medical conditions like Alzheimer’s Disease or stroke that can cause dementia; (3) suffer from mental decline resembling dementia as a result of dehydration, medication side effects, or drug interactions; or (4) develop a neurocognitive disorder that is mild to moderate in nature but may require special testing to diagnose.

Epidemic/Pandemic

An epidemic is an outbreak of disease across a population; a pandemic is even more wide-spread, often crossing national boundaries. HIV/AIDS is both an epidemic in the US and a worldwide pandemic.

HAART/Combination Therapy

Short for “highly active antiretroviral therapy.” HAART refers to a treatment approach in which multiple ARV from different classes are taken in combination to treat HIV infection (sometimes called *combination therapy*). HIV mutates quickly, sometimes making the virus less vulnerable to certain medications over time (*treatment resistant*); combination therapy helps to protect against this.

Harm Reduction

Refers to a practical approach to risk reduction that acknowledges that people may choose to engage in risky behaviors and aims to help them be “safer” while doing so. Safer sex tips and *needle exchange* programs (where used syringes are traded for new ones) are examples of harm reduction strategies.

HIV

Short for “Human Immunodeficiency Virus.” HIV attacks a person’s immune system, making it more difficult for their body to fight off infection. A person infected with HIV is said to be “HIV-positive,” or “Positive”; a person who does not have the virus is “HIV-negative,” or “Negative”. There are two types of HIV: *HIV-1* is most common worldwide and is what most Americans mean when they talk about HIV; *HIV-2* is found mostly in West Africa. Medications effective against HIV-1 do not necessarily work against HIV-2.

IDU

Short for “intravenous drug user.” A person who uses syringes to shoot drugs directly into their body. Sharing injection equipment puts IDUs at high risk for HIV and other infections, such as hepatitis.

LGBT (or GLBT)

Short for “lesbian, gay, bisexual, and transgender people.” Often used to reference the diversity within what some refer to as “the gay community.” Sometimes also includes the letter “Q” for both “questioning” and “queer,” a term historically used as a homophobic slur that has been reclaimed by some who reject more mainstream definitions of sexuality.

MSM

Short for “men who have sex with men.” A term used to describe men who have had sex with one or more men, regardless of whether they consider themselves to be gay, bisexual, “only experimenting,” or do not label their sexual orientation in any of these ways.

Neuropathy

Nerve damage that can occur anywhere in the body, but often used as shorthand for *peripheral neuropathy* which occurs in the hands, feet, arms, and legs. Sensations can include pain, tingling, burning, numbness and paralysis. Can result from HIV infection or as a side effect of some medications.

Opportunistic Infections (OIs)

Illnesses that take advantage of weakened immune systems. A person with HIV who develops one of these infections or cancers is said to have “progressed” to an AIDS diagnosis. For a complete list of these *AIDS-defining conditions*, visit the CDC’s HIV/AIDS home page (included in our “Resources” section).

PCP

Short for “Pneumocystis Carinii Pneumonia.” A life-threatening form of pneumonia particularly common in people with weakened immune systems and the most common “opportunistic infection” affecting people with HIV. PCP is an “AIDS-defining condition,” meaning that an HIV-positive person who develops PCP has progressed to an “AIDS” diagnosis.

STI/STD

Short for “sexually transmitted infection/disease.” Many STIs cause breaks in the skin, increasing the risk for sexual transmission of HIV. Condoms can protect against both STIs and HIV.

Strain

Some viruses, like the common flu or HIV, evolve rapidly into different versions or strains that may not

respond to the same antibodies or medications that effectively curbed the original strain. This is why flu vaccinations are more effective some years than others, and why HIV medications that may initially work well for a patient can stop working over time.

Universal Precautions

Techniques used by health care professionals to protect themselves and others against the spread of disease (including use of protective equipment, like gloves, and the proper disposal of medical waste, like used syringes). In most interactions with patients with HIV/AIDS, goggles and face masks are unnecessary.

Viral Load

The amount of HIV in an infected person’s blood. Usually, when a person’s viral load goes up (meaning they have more virus in their body), they become sicker and are at greater risk of transmitting HIV to other people. As there is currently no cure for HIV, the goal is to reduce their viral load to *undetectable* levels—so low that the virus cannot be detected by available tests.

Wasting Syndrome

Involuntary weight loss (at least 10% of body mass) in combination with diarrhea, fever, or weakness lasting at least 30 days. The bulk of what is lost is “lean body cell mass,” meaning that while it may be a combination of muscle, fat, and bone, it is mostly muscle.

Modes of Transmission

Anyone can become infected with HIV. It's not “who you are” but “what you do” that puts you at risk if your partner happens to be HIV-positive. The most common ways for people to become infected with HIV in the US today are through unprotected sex and sharing needles.



CHOOSING NOT TO HAVE SEX OR SHARE NEEDLES is the most effective way to avoid possible exposure to HIV, but there are other very effective ways to reduce the chances of transmission and increase your chances of staying healthy. If you are HIV-positive, one of the best ways to protect your partner(s) is to take care of yourself: recent studies suggest that if HIV-positive people use antiretroviral drugs to reduce their viral load to “undetectable” levels, the risks of transmitting HIV to their sexual or drug using partners decrease significantly.

To prevent transmission through sex:

- Get tested for HIV and know the status of your partner(s). You cannot tell if a person is HIV-positive just by looking at them; the only way to know for sure is to get tested. HIV tests look to see if your body has developed antibodies to the virus. Most people will develop HIV antibodies within three months of exposure: some people will develop them sooner, and a few may take as long as six months. If your test comes back “negative” three months after exposure you can feel pretty confident about your results, but because the length of each person’s “window period” can vary, some test centers may encourage you to retest six months after exposure, just to be sure. It is possible to pass HIV on to another person during this window period, even if you do not yet test “positive.”
- Use latex or polyurethane condoms (or other barriers like female condoms or dental dams) during vaginal, oral, and anal sex.
- Use a water-based or silicone-based lubricant, which minimizes the risk of tearing (of condoms and of delicate skin) that can result from friction during sex while also increasing sensation.
(Avoid lotions and Vaseline because they can cause condoms to break.)

To prevent transmission through needle use:

- Do not share your needles or “works” with other people, whether you are using needles to inject drugs, hormones, or medications like insulin. While HIV generally does not survive for long outside of the human body, it can survive for weeks inside a syringe.
- If you absolutely must share needles or works, be sure to clean them very thoroughly (water, then bleach, then water again) to avoid transmitting HIV and other blood-borne infections like hepatitis.
- Many communities now offer free needle-exchange programs; in some states, you can buy new needles from a pharmacy without a prescription.

For transmission to occur...

...the virus needs a direct pathway out of the body of a person who is HIV-positive.

...the virus needs a direct pathway into another person's body.

HIV lives in high concentrations in certain body fluids:

- blood (including menstrual blood)
- semen (cum)
- vaginal fluids
- breast milk

There are lower concentrations of HIV in pre-seminal fluid (pre-cum), making transmission less likely but still possible.

Healthy skin is an excellent barrier to HIV. The virus can pass into another person's body through:

- broken skin (small sores, tears, and cuts can act like an open door into a person's blood stream)
- direct contact with a person's blood (like when needles are used by more than one person)
- mucous membranes (like those inside the vagina, tip of the penis, anus, rectum, mouth, and eyes)
- from mother to baby before or during childbirth, or through breast milk. This is less common in the US today, as women can receive treatment that dramatically reduces the likelihood of transmission to their baby.

There is not enough virus to make another person sick in: saliva, sweat, tears, urine, or feces.

HIV is not transmitted through casual contact.

The virus does not:

- move through the air, like the common cold
- travel through food, like E. Coli
- get transmitted through mosquito bites, like malaria
- bore through healthy skin, like some parasites

You cannot get HIV from:

- shaking hands or hugging a person with HIV/AIDS
- using a public telephone, drinking fountain, restroom, door knob, silverware/dishes, swimming pool, or hot tub after a person with HIV/AIDS
- sharing a drink or a meal with a person with HIV/AIDS
- being coughed or sneezed on by a person with HIV/AIDS
- giving blood
- being bitten by a mosquito

For more on the topics addressed above, talk to your doctor, see our glossary and resource sections, and go to our website, www.grayingofaids.org.

People in the US no longer need to worry about getting HIV from transfusions of infected blood or blood products. Most infections in medical settings result from accidental “needle sticks” with a needle that has already been used on a patient with HIV, and primarily involve health care professionals.

To protect themselves and their patients, providers should always use universal precautions:

- Wear latex gloves when coming into contact with blood, breaks in the skin, and mucous membranes.
- Only use needles and gloves once, then discard.
- Wash hands often, including after discarding medical waste.
- Dispose of materials exposed to blood (like needles) properly.

Resources and Links

Partial List of Useful Links to Learn More About HIV/AIDS.
For more detailed information see www.grayingofaids.org

AIDSmeds

Provides people living with HIV with the up-to-date information they need to make empowered treatment decisions.

www.aidsmeds.com

AARP

A nonprofit, nonpartisan membership organization that aims to enhance the quality of life for all people as they age by advocating for positive social change, conducting aging-related research, and connecting members

with valuable information and services.

www.aarp.org

AIDS Community Research Initiative of America (ACRIA)

Home to The Center on HIV & Aging. Conducts and supports medical and social science research on HIV/AIDS, advocates on behalf of people living with HIV, and promotes HIV health literacy through treatment education programming and publications. Includes link to ROAH study.

www.acria.org

American Academy of HIV Medicine (AAHIVM)

Committed to supporting providers in HIV medicine and ensuring better care to those living with HIV/AIDS. Website has a “Find a Provider” function which connects patients with credentialed HIV specialists in their area.

www.aahivm.org

Association of Nurses in AIDS Care

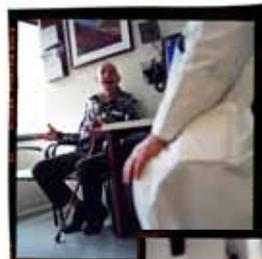
Promotes professional development for nurses working with People Living with HIV. Includes public policy and advocacy information and links to professional development resources and ANAC chapters/activities.

www.nursesinaidscare.org

The Body: The Complete HIV/AIDS Resource

A great source of information about HIV/AIDS and living well with the virus. Useful features include a comprehensive glossary, “Ask the Experts,” “Personal Stories,” and bulletin boards to help people connect and share information.

www.thebody.com/index/whatis/older.html



Broadway House for Continuing Care

New Jersey's only special care facility for People Living with AIDS, and the community-based organization partner of *The Graying of AIDS*.

www.broadwayhouse.org

The Centers for Disease Control and Prevention (CDC)

A component of the US Department of Health and Human Services, the CDC coordinates research, promotes the sharing of knowledge, and tracks trends in the HIV/AIDS epidemic. Information and links, in English and Spanish.

www.cdc.gov/hiv

Center for Excellence in Transgender Health

Provides leadership, capacity building, professional training, policy advocacy, research development, and resources to increase access to culturally competent health care for transgender people in the US.

www.transhealth.ucsf.edu

Family Caregiver Alliance (National Center on Caregiving)

Provides links to education and training, research, on-line services, and more; often described as a “one-stop shopping center for caregivers.”

www.caregiver.org/caregiver/jsp/home.jsp

Gay & Lesbian Medical Association

Works to ensure equality in health care for LGBT individuals and health care professionals. Site includes resources for patients, providers, and researchers, including a “Find a Provider” link.

www.glma.org

Gay Men's Health Crisis (GMHC)

The world's first HIV/AIDS care and advocacy organization. Their comprehensive website

provides access to a wealth of information, including informative, downloadable reports like *Growing Older With the Epidemic: Aging and HIV* (2010).

www.gmhc.org

The Harm Reduction Coalition

Provides information about the principles and practical realities of

harm reduction, including policies and procedures that address the adverse affects of drug use.

www.harmreduction.org

HIV InSite

A resource created by the University of California at San Francisco that provides up-to-date information on HIV/AIDS prevention, treatment, and policy.

<http://hivinsite.ucsf.edu>

Lambda Legal

A national organization committed to achieving full recognition of the civil rights of LGBT people and those with HIV through impact litigation, education and public policy work.

www.lambdalegal.org/help

National Association of People with AIDS

Provides leadership development, capacity-building and consumer advocacy programs, and conducts policy advocacy on behalf of People Living with HIV/AIDS

www.napwa.org

National Institutes on Aging (NIA)

Part of the National Institutes of Health, NIA's web site includes information for and about older people with HIV/AIDS in both English and Spanish.

www.nia.nih.gov/HealthInformation/Publications/hiv-aids

National Resource Center on LGBT Aging

The country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to LGBT older adults, established in 2010 through a federal HHS grant.

www.lgbtagingcenter.org

National Senior Citizens Law Center

Through advocacy, litigation, and the education and counseling of local advocates, this non-profit organization seeks to ensure the health and economic security of those with limited income and resources, and access to the courts for all.

www.nsclc.org

Poz

This award-winning print and online periodical addresses the diverse needs of people living with and affected by HIV/AIDS, including treatment updates, investigative features, videos, blogs and an extensive online social network.

www.poz.com

Project Inform

Advocates for a compassionate response to the HIV epidemic by government, academia, industry and community, and connects people living with HIV with information necessary to make informed health decisions. In English and Spanish.

www.projectinform.org

Rural Center for AIDS/STD Prevention

Provides current prevention resources to professionals and the public and develops, evaluates, and shares materials and strategies specifically designed to overcome barriers to rural HIV/STD prevention.

www.indiana.edu/~aids

The San Francisco AIDS Foundation

Website offers a variety of helpful fact sheets, resources, and links, including a comprehensive glossary of HIV-relevant terminology.

www.sfaf.org/custom/glossary.aspx

Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)

Addresses the gaps in sensitivities and services that often leave GLBT seniors under-served and can send them "back into the closet." Website includes information on resources, policy and New York programs, with links to affiliates around the country.

www.sageusa.org/programs/partnerships.cfm

US Department of Health & Human Services Administration on Aging (AoA)

Supports a comprehensive, coordinated system of home and community-based services to help elderly individuals remain healthy and independent. Includes links to *Eldercare Locator Website*, *The BenefitsCheckUp Website*, and a range of services funded under the Older Americans Act.

www.aoa.gov

US Department of Justice Americans With Disabilities Act (ADA)

Know your rights and responsibilities: people living with HIV/AIDS are protected by the Americans With Disabilities Act. Includes resources like a toll-free hotline that permits businesses, state/local governments, or individuals to ask questions about ADA requirements.

www.ada.gov

Women Organized to Respond to Life-Threatening Disease (WORLD)

Emphasizes peer-based advocacy and education for women living with HIV through programs like "The Lotus Project," a national skills-building peer advocacy training, and "Positive Women's Network," which encourages positive women to impact policy that affects their daily lives.

www.womenhiv.org



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- Using a tone or speaking style when talking with an older person that is similar to the style one might use when talking to a small child
- See for example, Emlet CA. (2006) "You're Awfully

Get Involved

Educate yourself. Whether you're an older adult, a care provider, or a concerned family member, friend, or community member, our extended "Resource Links" (www.grayingofaids.org/resource-links) can connect you with valuable information.

Talk about it. HIV/AIDS persists in part because all the things we find it difficult to talk



about as a society – sex and sexuality, substance use, ageism, racism, classism, and homophobia – contribute to its survival. The more we confront these cultural taboos and prejudices and work together to decrease their reach and power, the less they will act as barriers to critical education, support, treatment, and public policy changes.

Do Something! There are amazing organizations working on the local, state, and national levels to address both the day-to-day challenges confronting older adults living with HIV/AIDS and the larger policy issues that impact their daily struggles. *Volunteer* to help people get to their appointments and go grocery shopping; *lobby* your representatives to support universal access to health care and critical life-saving programs like ADAP (AIDS Drug Assistance Program); and yes, *write those checks* – in economically challenging times, not-for-profits depend on your support to continue their work.

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Sex education is not just for kids and condoms are not just birth control.

“**HOW WILL I EVER TELL MY CHILDREN?**” In my work with seniors who have contracted the HIV virus, I have heard this lamentation and others like it many times. Men and women over 50 are living with HIV in never seen before numbers.

Our mission as health care providers to the geriatric set is changing quickly; we must expand our specialty to include preventing and treating HIV/AIDS just as quickly.

It is no longer acceptable to expect that our older clients are not at risk. Age is not a vaccine. We must be brave enough to conduct a sexual history, wise enough to think of HIV as a diagnostic possibility and supportive enough when the results confirm HIV-positive.

—Jeanine Reilly
Broadway House, Newark

- Sex education is not just for kids and condoms are not just birth control.
- AIDS stimulates and simulates aging. We must include an infectious disease practitioner as well as a geriatric practitioner in the care team and learn the differences as well as commonalities between the two specialties.
- Provider fear around AIDS contagion still persists. Education must be provided to all levels of caregivers, beginning at the top of your organization.

Coordinated care is critical. Let's work together.

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