AGING WITH HIV

Laura Wilhelm, PhD

We live in a society where setting and reaching personal goals drive many individuals’ daily lives. We like to “get results” and “make things happen” – ideas that are reinforced from the time we are very young. On the other hand, we don’t like to lose, despite the fact that experiencing loss is an inevitable part of life. The losses that we experience as we age can be especially painful.

Aging with HIV/AIDS has its own unique set of challenges. The good news is that medications allow people to live much longer; the not-so-good news is that a lot of unknowns go along with getting older. Coping with a chronic illness involves multiple stressors – some seem to get easier over time (e.g., taking medication correctly, communicating more openly with your doctor); others may become more difficult (e.g., living with the side effects of medication, tolerating unexpected bodily changes). At some point, everybody who is HIV-positive wrestles with the unpredictable that comes with both aging and the virus. The following are common thoughts of older adults living with HIV/AIDS:

- I never thought I would live this long.
- When I believed I was going to die from AIDS, I let everything else in my life fall apart.
- I've always relied on my appearance to get me through, and now it's failing me.
- I can’t believe I have to take another medication.
- Why is this happening to my body—is it the virus, my medications, or because I'm getting older?
- If only I had known then what I know now…

No matter how discouraging things feel at times, remember that you are not alone. While you may not have family or friends’ support, new healthy bonds can be formed if you’re willing to work at it. Recognize that you have choices for a better quality of life. Focusing on the negatives can make a person feel trapped. Loss and disappointment—both related and unrelated to HIV—are going to happen.

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Never Too Old

People over the age of 50 may not think of themselves at risk of getting infected with HIV. But if you’re having sex outside of a mutually monogamous relationship in which you both know each other’s HIV status, don’t kid yourself.

Common sense practices:

- Abstain from sex (do not have oral, anal, or vaginal sex) until you are in a relationship with only one person, are having sex with only each other, and each of you knows the other’s HIV status.
- You may be newly single, through divorce or death of a partner. It is important to have the facts about HIV before beginning to date and have sex with someone new.
- Even if you think you have low risk for HIV infection, get tested whenever you have a medical check-up.

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President Obama Signs Ryan White CARE Act of 2009

President Obama has signed the Ryan White CARE Act Reauthorization Bill of 2009 into law. The legislation will continue to fund vital AIDS/HIV programs through until 2013 with a funding increase of up to 5 percent through all sections of the program, and stipulates a national goal of ensuring 5 million HIV tests are carried out annually.
Aging

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Remember that bad feelings aren’t facts. When you are living with HIV and the challenges that go along with aging, it is vital to stay positive and commit to steps that promote a higher quality of life.

1. Take good care of your body – this becomes even more important for aging with HIV/AIDS. Quitting smoking and other recreational drugs, limiting alcohol, eating healthy foods, getting regular exercise, keeping your mind active, and staying on top of your medical condition are life-enhancing strategies.

2. Develop and maintain an active support system – building and preserving healthy relationships with family, friends, and perhaps some unexpected sources of support improve both the good times and the bad.

3. Remind yourself of the parts of your life that you are grateful for.

4. Perform random and planned acts of kindness

5. Be mindful of life’s small treasures – whether you are HIV-positive, there are other issues that they face that complicate an HIV diagnosis. Dorothy and Liz share that the primary emotional and spiritual challenge faced by HIV-positive women over fifty is isolation. “If you’re single and over 50, it is hard to go out and look for someone, even more so if you are HIV-positive,” says Dorothy. “Yeah, if you’re single its tough,” confirms Liz, “and if a woman is married, what’s there to negotiate? I got it from my second husband and that’s the hurtin’ thing – when you know you were faithful to only one man.”

These are not uncommon stories for any woman who acquires HIV. Yet, for women who are older than 50 there are other issues that they face that compound an HIV diagnosis. Dorothy and Liz share that the primary emotional and spiritual challenge faced by HIV-positive women over fifty is isolation. “If you’re single and over 50, it is hard to go out and look for someone, even more so if you are HIV-positive,” says Dorothy. “Yeah, if you’re single it’s tough,” confirms Liz, “and if a woman is with someone, then the disclosure part is hard. Then there is the self-blame, the guilt, and the shame.” Dorothy goes on to suggest, “If an HIV-positive women is over 50 and has a man, she’ll do whatever she can to keep that man. These women are scarred of losing their men. Especially if this man already knows about her status. Sometimes a woman will go through hell just to keep that man,”

For women who are HIV-positive and over fifty the sense of stigma is also compounded because of age. “Stigma is different for women – and for older women especially,” says Dorothy. “There’s more shame.” While the stigma older woman experience may be similar to what other women face, there is the added judgment around an older woman who acquires HIV. Both Liz and Dorothy confess that a lot of people think more about older women and wonder, “How did she get it?” As Liz says, “There’s a sense you get from people that we shouldn’t have gotten it in the first place.” Dorothy adds that there’s also the added challenge of expectations from children and grandchildren. “Your kids don’t think that you’re having sex.” Older women often are not seen as being sexual.

Dorothy and Liz describe similar experiences of seeing older women at an AIDS clinic and not being sure of how to reach out to them. Liz shares, “They just pass by and turn their heads. It makes me wonder how I can start a conversation with them. I want to let them know, ‘You’re not alone. I know that it feels like that, but you gotta step out there on faith, you gotta talk about your fears.’ But I see the shame and the fear in their eyes.” Dorothy’s experience was similar. “A woman wouldn’t even look at me. We both know what she’s there for – what I’m there for. It’s hard. I wanted to talk to this older lady so bad – she looked at me and just turned her head. I wanted to tell her about WORLD and that there are other women living with this.”

The isolation and fear that older women face is further compounded by the lack of resources specific to their needs and interests. When asked what resources are available to older positive women, both Dorothy and Liz agreed that there are not enough resources for women over 50. Even regular support groups for women don’t address the issues of older women. “A support group for older women would address the difference in values that older women have,” suggests Dorothy. Liz adds that she sometimes has feelings that come up in the groups with younger women. “It makes me remember what it was like for me at that age and how it’s different for me now.”

They both offered advice to older HIV-positive women about seeking support. “First, they got to find strength within themselves,” Dorothy says. Their advice for each woman would be different. “There’s the woman who wants to stay home and bake cookies for the church social – do it!” says Liz. “Don’t let HIV limit who you are and what your life is!” She adds, “I can choose to isolate or I can choose to get up and get out into the world. There are choices.”

Women can find support through a group, or through their church. But what’s most important is that a woman finds a friend that she can trust. “Choose who you talk about it with carefully and you don’t have to tell everyone,” says Dorothy. “Learn about the disease! The more you know, the more you understand, and the less frightening it can be,” Liz advises.

For those women who are living with HIV in remote areas, they suggest that you may have to go a long way to get care. Don’t let that get in your way -- you need to get care. Find other women who may be close to you who are also living with HIV (ask your doctor to hook you up). Support each other, start your own group if you need to. If you know how to access information on the computer, get as much information as you can from websites on women and HIV, particularly older women living with HIV.

Above all, remember that all of the things we’re suggesting take time, just take it step by step and remember though you may feel like it, and it may be hard to believe, you are not alone!

This article was provided by WORLD Newsletter a publication of Women Organized to Respond to Life Threatening Diseases (www.womenwithhiv.org)

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Take the test!
The decision to be tested for HIV is the first step in taking responsibility for yourself and the health of others with whom you may be intimately involved.

**HIV testing locations**

Many testing sites offer free testing, but some charge a fee. Some locations require an appointment; others accept walk-ins. Call ahead to be sure! On the Internet you can find a list of test sites in your area by entering your zip code. Go to www.hivtest.org

**By phone, you may call:**

WV AIDS/STD Hotline: 1-800-642-8244

CANC Ryan White Program care coordinator in Charleston:

(304) 388-9337 or toll-free: 1-877-565-4423

National HIV/AIDS Hotline: 1-800-342-2437

Your local county health department
We came from the same era," explains Liz. "We believed that our men were there to take care of us. We had the expectation that when you’re going out with me it’s just me." Dorothy adds, "Now we know that’s not true. When you’re married, you don’t think about condoms. You’re not thinking about what he’s doing when he goes out with the guys."

Dorothy was married when she found out she was HIV-positive. "If I had caught the clap [when I was young] I might understand. Then in my elderly age I get this. I catch HIV! That was a shock," says Dorothy. "At first for me it was disgust," says Liz. "But I know that I had a healthy sex life and it was about expressing my love. Maybe I could have put on a condom more -- but we don’t have the power to wear a condom or even negotiate it with our men." Dorothy adds, "And when you’re married, who’s there to negotiate? I got it from my second husband and that’s the hurtin’ thing -- when you know you were faithful to only one man."

These are not uncommon stories for any woman who acquires HIV. Yet, for women who are older than 50 there are other issues that they face that complicate an HIV diagnosis. Dorothy and Liz share that the primary emotional and spiritual challenge faced by HIV-positive women over fifty is isolation. "If you’re single and over 50, it is hard to go out and look for someone, even more so if you are HIV-positive," says Dorothy. "Yeah, if you’re single it’s tough," confirms Liz, "and if a woman is with someone, then the disclosure part is hard. Then there is the self-blame, the guilt, and the shame." Dorothy goes on to suggest, "If an HIV-positive woman is over 50 and has a man, she’ll do whatever she can to keep that man. These women are scared of losing their men. Especially if this man already knows about her status. Sometimes a woman will go through hell just to keep that man,"

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