

Conversation with a Person Living with HIV

Summarized by Chris Chapman, MA

Chris Chapman spoke with a person living with HIV on August 6, 2020. The following is a summary of that conversation. The individual interviewed preferred not to use their name, so we will call the patient “Ryan” in honor of Ryan White. Please read the article to learn more about why the patient preferred not to use their name.

Chris: How long have you been living with HIV, Ryan?

Ryan: About 14 years

Chris: Talk about how you found about your HIV diagnosis and how you felt after you found out.

Ryan: I was in the hospital after a car accident and they ran some tests. One of them was for HIV and a doctor came to my room to tell me I had HIV. I didn't really feel anything after he told me, I felt numb. I wasn't expecting anything like that. I never thought a person like me could get HIV. I'm a straight man and I thought HIV only affected gay men. Now I know it can affect anyone.

Chris: Can you tell us about how you felt about getting treatment after you were first diagnosed?

Ryan: The doctor that told me about having HIV told me that I should start treatment the next day. I didn't object to that; I did what they told me was best. The clinic I went to was inside a hospital and very private. Nobody knew what kind of a clinic it was; there were no signs that said “HIV” or anything like that. This was a clinic in the Chicago area.

Chris: How did you work through accepting your HIV diagnosis?

Ryan: There was a counselor at the clinic. She took me aside and walked me through what to expect. She told me that HIV was not a death sentence and that I wouldn't die from HIV, but probably something else. I thought my life was over but she really calmed me down and helped me out a lot. She's still working at that clinic. She also got me involved in a support group for people living with HIV (PLWH). The group met every other week and we had lunch together. Most of the people in the group were older, around the same age as me; I'm in my 50s now. They were pretty calm in the way they talked about having HIV and they really took me under their wing. I would have been “blind” about living with HIV without them.

Chris: Tell us about disclosing your status to people in your life. How did you decide whom to tell?

Ryan: I decided to tell some of my close family members. One night I told them I had HIV. They understood and accepted it, but we never talked about it again. It's like we put it in a closet and shut the door and never opened it up again. They didn't tell anyone else about my status either, because when you put that information out there, that you have HIV, sometimes people start talking about you and making assumptions, they stereotype. So, if I'm going to tell someone about my HIV status I have to feel it. I have to feel that they are open to hearing the real information about living with HIV.

Conversation (continued)

Chris: Can you tell us how HIV stigma has impacted your life?

Ryan: You can feel the stigma. When some people find out you have HIV, you can read the expression on their face, they start treating you differently. Some people stop calling you or stop coming around. You can feel the stigma when you walk into a room. People will look at you and start whispering. They look at you like you're an animal in a cage. This sometimes happens at medical offices. But I don't let it bother me, because if you let it bother you it can mess with you mentally. I just keep on going living my life and don't let others judge how I live my life. Because of this I am not using my name in this article.

Chris: Talk about what some of the biggest misconceptions people have about HIV.

Ryan: When people find out you are living with HIV, they look at you like you're about to die. You have to educate them and explain that it's not like that anymore; it's not a death sentence. People will also stereotype you and assume you were either a gay man or injecting drugs and this is how you got HIV. I used to think "never me" that HIV only affected certain types of people but it would never affect me. I learned that HIV does not discriminate and other people need to learn that it can affect anyone.

Chris: You are a member of the UW Health HIV Care and Prevention Program's Community Advisory Council (CAC). Can you tell us what the CAC is about and why you decided to become a member?

Ryan: The CAC is a group of patients of the program who are living with HIV. We meet every other month to talk about issues for PLWH and how we can make sure patients get the best quality of care at the clinic. Since I had been part of a support group back in Chicago that helped me, I wanted to be a part of this group to help other people. I like it because it's very educational and I hear about what's going on with the clinic and with HIV treatment.

Chris: Talk more about how you learned more about HIV and the latest treatment and medication options.

Ryan: I like to keep up-to-date on HIV, so I read a lot about it and self-educate. I read at home, visit different websites, and go to educational talks when the clinic offers them. I want to know if there are new HIV medicines out there so I can ask my provider about them. I feel like this helps me and helps my life.

Chris: What would you like to tell people newly diagnosed with HIV?

Ryan: I'd want to tell them that they're not alone. That living with HIV is not that bad. Also, they shouldn't be afraid to learn and to get support; they will need support. But not everyone is ready right away, some people retreat after getting their diagnosis. Every person is different, so when they're ready I want them to look at me and know that after 14 years I am doing fine and living well with HIV.

Chris: What do you want young people to know about HIV?

Ryan: I want them to know that they should practice safer sex. Condoms can be a lifesaver.

Chris: Thank you for sharing your story with us.

Ryan: Thank you for choosing me Chris!

Learn more at uwhealth.org/hiv

Update on Clinic Appointments and Services

By Cindy Wallace, LCSW

While the way we provide care may look different these days, be assured that the UW HIV Care and Prevention clinic staff continue to be available to support your health and wellness goals. Your safety is of utmost importance, so we continue with symptom screening evaluations and questions, social distancing and cleaning protocols. We are here to answer any questions or concerns you may have as we all try to navigate through these challenging times!

We thought now would be a good time to provide a few updates on services:

Appointments

A clinic nurse may contact you 1-2 weeks before your appointment. If you receive a call you can anticipate questions and discussions regarding the following:

- Appointment Visit Type
 - They may discuss the available appointment types which include in-person, telephone or video
- Labs
 - They will discuss when and where to get labs completed before your appointment if needed
- Your concerns
 - Please mention to the nurse if you have any specific concerns for your upcoming appointment to discuss with the provider or a member of the care team, like a pharmacist or social worker

If you would like to discuss specific questions or concerns before your scheduled appointment and have not received a call from the nurses, reach out to the clinic nurses at (608) 263-0946.

Pharmacy Services

All UW Health Pharmacy sites are now open!

- Curbside pickup at pharmacy sites is no longer available.
- Free mail and delivery options are available. Talk with a pharmacist about these options.

UW Health Pharmacy sites will provide appointment-only immunizations starting September 14.

- Appointments can be made via MyChart or by calling the pharmacy to schedule (only if you do not have MyChart).
- Only immunizations that are covered under your prescription insurance benefit or covered under the Ryan White program can be provided.

As always, please reach out to us by calling our main clinic line at (608) 263-0946. We are happy to hear from you and we will work together to address questions, concerns or hear your feedback.

[Learn more at uwhealth.org/hiv](https://uwhealth.org/hiv)

Accessing Community Resources during the Pandemic

By Eric Stanko, CAPSW

A lot has changed during the COVID-19 pandemic. Many of the resources and supports we use are doing things differently now. The good news is that these resources and supports are still available! A lot of us have relied on these things to meet our needs or get additional help with specific problems, and this may be more important than ever before with COVID-19. Our goal at UW Health is to make sure you get everything you need to live well, so we are providing this brief list of services to help during the pandemic.

Food Pantries

- Vivent Health (formerly ARCW): (608) 252-6540. Call ahead for pick up.
- Grace Episcopal Church: (608) 255-5147. ID is required.
- Beth Lutheran Church: (608) 257-3577. ID is required. Call ahead to register.
- River Food Pantry: (608) 442-8815. Proof of address required.

Prevention/Harm Reduction Services

- Vivent Health: 800-486-6276
 - Needle/syringe exchange, Narcan, condoms
- Public Health Madison Dane County: (608) 243-0411
 - Needle/syringe exchange, condoms, free STI/HIV testing

Clothing/Household Items

- Bethel Lutheran Church: (608) 257-3577
 - Adult-sized clothing
- Grace Episcopal Church: (608) 255-5147
 - Personal grooming supplies and toiletries
- River Food Pantry: (608) 442-8815
- St. Vincent DePaul Society: (608) 257-0919
 - Clothing vouchers

Useful Phone Numbers

- Journey Mental Health Crisis: (608) 280-2600
- Dane County United Way: 211 (call for various resources/services)
- Aging and Disability Resource Center (ADRC): (608) 240-7400
- Tenant Resource Center (TRC): (608) 257-0006
- UW Health HIV Clinic: (608) 263-0946

Your UW Health team is here for you. If you have questions, concerns, or just need to talk, your social worker is ready to help so please reach out to us!

Learn more at uwhealth.org/hiv