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## *AIDS THESE DAYS*

From PRI, Public Radio International, it's Outright Radio. I'm David Gilmore.

### Music

To begin our show today, I want to tell you a little bit about my best friend. His name was Sky. That's actually his music in the background. He was a musical genius, composer of love songs and at 41, Sky died of AIDS. In June of 1997 – His illness was just a little too advanced to take advantage of the modern drug treatments now seen as maintenance drugs for most people living with HIV/AIDS.

### Music

When Sky died that early June morning, he joined the ranks of a generation of extraordinary gay men, mowed down like soldiers in a battle they knew they would lose. Back then, it was almost a certainty that he would stagger off to a painful and drawn-out death. It was. And he did. I sat with him on his last day, holding the hand of a skeleton with big blue eyes. His team of caregivers and I walked him to that quiet clearing – that place between life and death...and then we let go.

### Music

It was only a year later that San Francisco's gay newspaper the Bay Area Reporter revealed its astonishing headline. On August 13, 1998, the paper that had published an average of 12 obituaries each week for 17 years printed in giant type on the front page: "No Obits." I sat stunned as I read it. The message was clear: the viral tide in the gay community had turned.

### Music

Today on Outright Radio, we'll take a deeper look at HIV/AIDS specifically in the gay community. We'll hear from some of the people thriving on the antivirals and we'll also hear about some of their pernicious side effects.

### Quotes:

Stephen: But after nine months of an intensive period of switching from drug to drug, from medication to medication, and each time having a very difficult adjustment to the medication um it became too much

We'll also take a look at how internalized homophobia has affected prevention efforts...

### Quotes:

How do we encourage gay men to really feel like their lives are worth protecting, that their lives are worth saving and as are those of their friends and lovers?

and finally, we'll hear from those who knowingly put their lives at risk...

Quote from Sam: "...after having gone through a couple of decades of -- becoming educated and becoming steadfast in not allowing myself to become infected, I let down my guard."

We hope you'll join us for the next hour as Outright Radio presents "AIDS These Days."

Theme song without words.

DG: When AIDS began snaking its way through the gay community in the mid 1980's it was like the opening battle scene from *Saving Private Ryan* – organizations were devastated, entire groups of friends decimated. Recently, a friend described a picture from Christmas 1983. Twelve gay men posed for the picture. Only three of the twelve survived. This is typical of the devastation to the gay community. But, six years later from that fateful Christmas photo, in 1989 the pharmaceutical company Burroughs Wellcome introduced AZT – the first chance at an effective treatment for the disease. Although it slowed the ravages of the disease, AIDS was still considered a death sentence.

Finally, in 1995, with 9.2 million people already dead from AIDS worldwide the Food & Drug Administration approved a new class of drugs. These "protease inhibitors" taken in combination with other NRTI drugs (the nucleoside reverse transcriptase inhibitor) had a remarkable effect on a patient's health. This combination drug therapy became known in the gay community as "the cocktail." These advances injected some much needed hope into the lives of many gay men whose blood work began to improve. Viral loads plummeted toward undetectable – T-cell counts nosed up. People with "category C" AIDS, who were hovering on death's door went home from the hospitals and hospices.

I spoke to Rick – a 50 year old man with "Lazarus Syndrome" – a term a term given to folks with AIDS who essentially came back from the dead. He's one of those amazing success stories whose combination therapy restored his health. I found him at the International Gay & Lesbian Aquatics – the gay version of a Masters swim competition, where he was competing with a thousand swimmers from around the world.

Rick Well, I've been telling friends and other swimmers here that I think swimming, along with my vegetarian lifestyle is what's keeping me alive...cuz I've had full-blown AIDS for 13 years and uh, I've had my ups and downs with it. People say I look really good right now which is nice for me to hear. It's always good for the ego. It's good to be competing. I enjoy it. I'm doing some good times.

DG: Tell me what it was like for you being at death's door...how long ago was that?

R: Well let's see, I think that was 1992, I was at death's door mostly because they couldn't stop me from throwing up. SO I was getting no nutrition and the residents that they had handling my case didn't really know what they were doing, so a personal friend of mine who's a doctor came and saw me in the hospital and just wrote out new orders for the residents as if she was my doctor and they followed her orders and she brought me back to life, basically. She cancelled all the orders they were doing and wrote new ones. So I owe it all to them.

DG: What anti-virals are you on now? I'm on some protease inhibitors. Some NRTI's and umm. The labels get so confusing. I'm on a lot of alternative therapies as well. DG: But you wouldn't be here competing at this swim meet if you hadn't been on some form of protease inhibitors...R: I think definitely the protease inhibitors saved my life and brought me back to where I can stand and exercise and have fun and travel and do all the things that I've always loved doing. DG: What competition did you swim today? R: I swam the 100 breast stroke which is the first time I swam it in 15 years. I was a little nervous about doing it. I wasn't sure which side of the pool I was supposed to be on and I got there right at the last second and basically threw my goggles on and dove in. So there was no time to get nervous and just had to do it.

DG: you're here and alive and competing. R: And I didn't throw up my meds. Believe me, that's a big challenge. DG: Biohazard in the pool. R: Exactly. Biohazard in the pool!

## Music

Well, with the combination therapy, things were definitely looking good for HIV/AIDS becoming a manageable disease...until the side effects began to surface. A short list includes: facial wasting, nausea, diarrhea, kidney stones, high cholesterol levels, sleep disorder, depression, cognitive and emotional difficulties and so on.

I spoke with some long-term survivors of HIV who are living reasonably well on the HIV combination therapies. Yet, both of them have been touched by the side effects that simply couldn't have been anticipated with their release in 1996.

When I spoke to Stephen, he had recently led the memorial service for a friend who had just died at age 53. He spoke of his friendship with Michael and how, together they navigated years of HIV treatments and their sometimes crippling side effects...

I moved here in 1990. He moved here in 1991. And we were friends and neighbors ever since and Michael committed suicide in... I think it was the first week of March, 2003, and...one of the contributing factors and probably, the most (stammer) probably,

S: What put him over the edge was his reaction to drugs - to HIV meds specifically and you know, I can't tell you that's what caused his death I mean, he was in many ways a troubled man and he had been for a long time, but he was he was very aware of, he was very aware of what his weak emotional spots were and he was strong enough to maneuver around them to work with them he was very well adjusted to his neuroses, he survived well - he eventually started doing antidepressants which helped him initially but he had this problem with medications, almost any medication could put him in a state of sort of borderline psychotic state, even certain antibiotics would have him on the edge of of psychotic - and what happened was as more and more HIV drugs became introduced, he needed more and more AIDS drugs, he needed to keep changing drugs because of the resistance to drugs that would develop and he needed different drugs, but when he changed drugs, the shakedown period to try to figure out if they work would become longer and longer and more difficult and more difficult and he would get, he would get - pretty crazy. I'd talk to him and he'd say well, I'm going through a really difficult time right now, but I'm going to switch meds and I'm going to the doctor for this and I'm going to try doing something, another combination and you'd say okay, okay, he's doing the right thing, he's going to the doctor he's switching meds - he was also doing what a lot of guys do -he was doing more than one doctor, he was doing a psychopharmacologist for the antidepressants, he was doing a regular MD for the, , HIV meds, and all of these meds were interacting and causing problems on a regular basis and the problems, the problems kept getting worse, and sometimes I'd see that it was just the drugs and I could stop and tell him that his mind wasn't telling him what was real and that what was happening wasn't reality and I would call him two or three times a day and talk him through that until he switched to something else until it became okay again or bearable again for a while

But after nine months of an intensive period of switching from drug to drug, from medication to medication, and each time having a very difficult adjustment to the medication it became too much and and and much to my shock but not really to my surprise, I got a phone call that he'd committed suicide.

He left a note to the housekeeper, um, um, apologizing, and, profusely and asking her not to go into the room but to call 911.

## Music

DG: Now, Gregg speaks about some of the disfiguring side-effects of the anti-retrovirals – a condition called lipo-dystrophy that causes the fatty tissues beneath the skin to redistribute abnormally, resulting in hollow cheeks, fat deposits under the chin and neck, and distended belly. The net result is that it leaves the patient looking old and tired.

G: I think there are realities of the illness that are painful and seem to someone standing on the outside and saying, well, 5 years ago you were praying for your life and now you're going to complain because you have a pot-belly or b/c you have sunken cheeks. I think that it can be devastating to any person to see such an enormous change in their body in such a short period of time that it just wreaks havoc on one's self-esteem and then one's sense of hope, one's sense of having something to live for... I mean if people are single – the idea of ever being able to find a partner and feeling that you're disfigured – there's some real powerful, powerful stuff. I know that for myself...

There was a time when my face was even more sunken where I remember crossing the street as to not have to come in contact with an old friend that hadn't seen me in a couple of years and to explain, you know, like because everybody would be holding your hand with both hands saying how are you *really*? And they think like you're ready to like kick the bucket any minute and you're like, I'm on the protease inhibitors - I've a million t-cells, shut the f--- up. So it's just like so frustrating to have this, these treatments that are saving you and at the same time wreaking havoc on your body in other ways. And we also don't know that the, the...we know that they're wreaking on it besides on just whether or not you look cute- they're also wreaking havoc on the internal organs and all this stuff and the heart and so I mean we don't know what long term damage is being done - I mean we do know, we just don't know exactly what turn that's going to take.

Music

DG: Not everyone suffers from negative side-effects of the combination therapy and clearly certain of these meds are more likely to cause the side-effects than others. It also depends on the host – many people respond quite well to the NRTI drugs without any side effects. Unfortunately, the meds that are most effective as anti-virals tend to produce the most pronounced side-effects.

And then, of course, there's the resistance to the drugs: the August 8, 2002 New England Journal of Medicine reported that between 1995 and 2000, any form of resistance to the anti-virals dramatically increased from 8% to 22% - a chilling statistic that has pharmaceuticals companies rushing to address the need for new meds. For the most part they have been able to keep up with the pace of the mutating virus but have begun only recently to fall behind.

One of the secondary side effects of the anti-retro-virals is that the meds have reduced the visibility of AIDS in the community. Much like seeing films of bloody car accidents in driver's ed in high school, the visual presence of death in the gay neighborhoods was considered a fairly effective prophylaxis, with the new infection rates dropping each year. But times have changed. From 2001 to 2002, the Centers for Disease Control and Prevention reported a 7.7% increase in new infections among gay men and a 17% increase since 1999 when new infections were at their lowest point. Considering that 50% of all new infections in the gay community are men under 25, we can conclude that half of the newly-infected were too young to witness the previous generation's demise...and the other half have forgotten.

Music

Getting the safe sex message into the ears of those at risk has been especially challenging to the prevention community in the relaxed afterglow of the anti-virals. I spoke with 2 prevention professionals about how to they've had to tailor their messages to be effective. First, from northern California, we hear from Charlie Seltzer, the HIV Prevention Education Coordinator for the Mendocino County Public Health Department.

C: You know, for years, HIV prevention was targeted at HIV negative people and the message was, “don’t get this disease” – you know, “play safe wear a condom, and avoid risky behavior,” I think the higher ups in public health started to realize that while that was an important message it was missing a very important piece and that’s targeting HIV prevention messages at the people who have HIV. You know, if everybody who had HIV knew it and said I will not pass this disease on to anybody, we wouldn’t need HIV prevention messages targeted at the HIV negative people. We could target all of our HIV prevention at the HIV positive people. And, um, this is the first year we’ve specifically written into our contracts that the agencies that we’re funding have to do HIV prevention for their HIV positive clients.

I asked Charlie to shed some light on barebacking – the term used for anal intercourse without condoms – clearly the most risky behavior, that some people practice **with the knowledge** that the encounter may include transmission of the virus.

C: There are, um, you know, bug chasers they’re called. There’s controversy in the HIV prevention field about just how prevalent this really is, um, but I remember reading classified in the gay newspapers and sometimes you’d see ads for people who say, “HIV negative- want the gift,” or “I’m HIV negative and don’t need safe sex.” You know, somehow people were letting the reader know that they’d do anything. They weren’t trying to protect themselves.

### **Track 19:**

C: You know, there’s there’s a life urge and there’s a death urge - in people. There’s a sense that death is going to happen to each of us and that it’s part of the inevitable unfolding of a life - and many people feel called by death. And in some people that call is louder than in others.

C: When I’ve traveled back to San Francisco, I’ve met friends who, who are recently infected. People I think who should have known better, who did know better, and they were playing risky, they were playing the edge, they were playing Russian Roulette with themselves or they simply- they thought it was inevitable that they were going to get infected and so they didn’t take precautions - they kind of forced the issue and said alright, finally I have it, now I can stop worrying about getting it – I’ve got it.

DG: For those of you in the HIV prevention business, I mean, that must very frustrating to be chasing this moving target.

C: I can’t see why anybody would want this disease. I mean, I lived through the first awful era of AIDS, before there were any medications for it and I saw, you know, I saw partners and friends and fellow musicians die of this disease. I saw lots of people die even after the medications came into being, because they simply didn’t work for those people or their disease was too far gone and their medications couldn’t pull them back. I think, you know, for a long time HIV was kind of glamorized, you’d read in the gay press, these advertisements of these hunky, very sexy bodies climbing mountains and and the advertisement said you know, something like- with this drug I’ve got my life back again - and it gave the impression that HIV was not a serious disease. That, you know - take this one pill once a day and you can climb mountains and have this great looking body. And I think it gave, it gave the wrong message.

I asked Charlie if he could put himself in the mind of someone who has lost the willpower to practice safe sex – that perhaps if we could do that, then we’d have a clear vision of a more effective prevention message.

C: I think being gay can be a very rough road for a young person before they come out. Um, it can be a rough road after you come out. I think there’s a lot of ways in which, um, anybody’s who’s different, whose forced to live in a conforming society, but especially gay people, we close parts of ourselves down in order to survive. We, we deaden ourselves, the place where our spirit resides takes up a smaller and smaller part of our heart, in

some people it it that spark seems to be extinguished – entirely. But I think it leaves lots of gay people hungry for sensation. Hungry for excitement - because we've been forced to shield ourselves in armor, armor plate ourselves to protect ourselves from a world that doesn't want us, where we don't feel like we fit in, where we feel like people don't like us. So, start with that kind of a psyche, add drugs, and, and you know, in some people you've got a prescription for risk taking behavior. You've got a prescription for, "please infect me." You know, another part of the equation in the gay community is that – you know, before aids came along, there was amazing political progress being made in the gay community around equality, equal rights, equal housing amendments, equal employment. There were lots of these politically motivated movements in the gay community.

C: When AIDS came along, all of lot of that had stopped. Or a lot of it stopped. And it had to because our community was sick. We had friends who were sick, we had friends who were dying, we had to take care of them, and I think people with HIV got all the attention. As, as they should have. And Um, and I remember talking to a lot of HIV negative gay friends when I lived in San Francisco talking about how the community – what tied the community together had shifted and it was now HIV that tied the community together and people with HIV were sort of the heart of the community. They were the people – our compassion went to them. All the service organizations that sprang up sprang up to take care of them and lots of HIV- people felt like we were somehow being overlooked.

## Music

DG: The CDC reported nearly 42,000 new HIV infections in 2002. A little less than half of those are gay men. I asked Shana Krochmal, Communications Director for StopAIDS Project in San Francisco to explain why we are seeing this rise and how they are addressing it...

S: Um, I think that, you know, three decades into the epidemic, we're seeing a real level of burnout, we're definitely seeing a lot of guys who either they've managed to stay safe for this long, you know, we really champion the men who have remained negative through 20 years of this epidemic and have really, really made a commitment personally to safer sex to their partners to whatever arrangement is they've made and even then, we're seeing, it's really difficult, this far in to continue that and as you see men start to age and they say you know, I'm 50 already, you know, and 20 years is all I'm going to have either way, so what difference does it make.

S: I think it's a, I mean, I think it's a combination of things - we're certainly challenged to figure out how to continually challenge the community to be responsible to itself. Right? How do we encourage gay men to really feel like their lives are worth protecting, that their lives are worth saving and as are those of their friends and lovers.

Shana also spoke about the pressures of society that are internalized by gays.

...sex is an easy way out of that. That's about escape. And that's a very understandable reaction to what, you know, we have in our lives every day to deal with, you know, we as queer people being told, you know what, we don't really care if you live or die. We're not going to put any valuable resources into the fact right now at all. In fact, we're probably going to turn around and figure out how to stop this at any point possible. We're going to try to shut down comprehensive prevention programs that allow gay men to speak openly and honestly about their sex lives, you know, we're going to tell you can't get married, tell you you can't have sex until marriage and just, you know, see where the chips fall and that's that's not helpful to anyone, that's not promoting safer sex or well being, or healthy behavior.

S: We're not in the business of saving lives, we're in the business of helping men build the skills they need to save their own lives - to believe that their lives are worth protecting and to have them help them to have the

communication skills they need in order to negotiate safer sex or to negotiate what it is they want out of a sexual relationship.

DG: Another factor enabling a spike in new HIV infection rates is the abuse of substances in the gay population.

S: We know that one of the biggest co-factors in infection here in San Francisco, but certainly something we're seeing increasingly around the country from men who have sex with men is the use of various substances, whether it's alcohol, whether it's crystal meth, whether it's crystal meth in combination with something like Viagra used recreationally, um, we spend a lot of time trying to talk to guys about why they're using substances or why they compulsively feel the need to have a lot of sex and a lot of drugs in combination with each other, what are they looking for, how is this playing into that, are they getting what they want, and how can we help them get into treatment if that's what they need. How can we help them feel better about themselves and their place in the community.

Music

DG: I spoke with a man named Milo who now has full-blown AIDS who fell into addiction with crystal meth in 1997. Although in Milo's case, crystal use was not a direct co-factor in HIS sero-conversion, he speaks of some of the negative side-effects of the drug and how the crystal sub-culture lends itself to infection and impairs the ability of people who are already positive to make healthy choices...

M: I was starting to get sick— when I started doing crystal on a regular basis. But I was still quite healthy. So it took a while of me doing it constantly for things to start breaking down. But when they did, I started hearing voices. I had auditory hallucinations. I lost 30 pounds. It certainly became a co-factor with HIV: it made everything worse. It made me sicker with HIV. It was sad to see myself becoming paranoid. Um not wanting to be around people. Wanting to only surround myself with other people who were on crystal. That was difficult.

I had a successful career. A successful life. A place to live. And in the space of a couple of years, I went to nothing. I lived in a residence hotel. And it was like going from being an active participant in society to a you know a crazy homeless person.

I lost just about everything I had in my life. I lost a place to live. I lost my job. I lost my sense of status in society, I lost my sense of dignity. And that was one of the hardest things.

DG: I asked Milo if he could explain the urge to combine crystal with sex and if he thought it was possible to do crystal casually...

M: I think Rufus Wainwright said it really well. He said there's no such thing as casual crystal use. Doing crystal one time won't kill you, but it's a hard drug. It's dangerous. In the gay community, I've seen a lot of people having problems with substance, with alcohol, with drugs and it's like one more temptation down a very very very dangerous road.

The borders of your reality break down and so it becomes easier for you to do things you wouldn't normally do. Whether it's from the drugs directly or the paranoia that you get from the drugs, it becomes easier to do things you wouldn't normally do. You want to explore further. You want to break down. Or you don't have the sense of the borders that you used to. So it becomes, if you're mixing sex and drugs, it only takes one time to have unsafe sex – to seroconvert – I know that from my experience directly. And so it becomes pretty easy if you're mixing sex and drugs to have unsafe sex once. And that's all it takes. I know that from my experience directly.

DG: But if you're HIV+ and you're doing drugs like crystal, do you think that's ultimately really destructive? Is there any way to be HIV+, do drugs and be healthy?

M: I think maybe...maybe there's one person in a thousand who can do that. It's possible to have a life of hope and to be healthy with HIV. But it takes a lot of commitment, energy. And it takes discipline. Consistency. Even just taking medications is a big deal. And it's work to be healthy for anyone. It's more work to be healthy and HIV+ and so if you're doing drugs, you're purposely stacking the cards against you.

DG: and you bring up a good point which is that if you're already positive and you're doing crystal, you're likelihood to engage in behavior that would infect someone else is much higher, right?

Track 34

M: Yes. It is. And the likelihood that the person you're with is doing crystal is going to be higher, the thing about safe sex is that it's not just one person's responsibility. It's everyone's responsibility if you're doing crystal, if you're both doing crystal. It's stacking the cards against keeping the boundaries of safe sex intact.

DG: I asked Milo what he would say to young gay men who are doing crystal...

M: I saw many people burn themselves out on crystal. To me, one of the most unfortunate things is, like HIV, crystal has taken away a lot of very bright, very intelligent people from life, taken them away from society. We need all the bright, intelligent people we can get...don't let crystal take you away. We need you. We need your brightness, your intelligence without it being taken away.

Long music break

DG: And so it seems that we cannot forge a comprehensive, effective prevention message – without first addressing the imprint of hatred on the collective psyche of the gay community.

Again, Gregg Cassin...

G: I think that what we're finding the most powerful prevention tool - really is building self esteem. And I think that we're finding that there's a program called Empower that is being that was produced I believe by UCSF Aids Project, and the most powerful tool that they're finding is by helping young gay men build an intimate community- a deep, deep sense of community, a deep sense of belonging, and a deep sense of their own self esteem and that that has been the most powerful prevention tool is that when people feel like they're important and that the people that they care about and know are important that it was keeping people from doing risky behaviors

And, I mean, just being loved and cared for and having that sense that there's a family that loves them and that brings and then that brings up back to remembering that there are a huge percentage of gay people that have been completely abandoned by their families and stuff, so there's all this sense of loss, and sense of what value do we have with the media, what the media says about gay people, and the things you can read in the newspaper, and republican senator saying awful things, and churches saying awful things, that it's a huge, it's a tide that, it's gay people swimming upstream of trying to get a hold of themselves, trying to have respect for themselves, love for themselves and care for their community and respect for their community. So, it's a lot of work, it's a lot of work

Music

DG: Again, Shana Krochmal from StopAIDS.

S: I think that when we talk about a vision for the future and when people have asked me, you know, so what do we need? We need a cure and we need a vaccine and I honestly I feel like if we lived in a world in which people felt like, you know, they could be a 15 year old gay boy in Iowa City and that that didn't make his life any less valuable than anyone else's he knew, that's as close as we're going to get to a cure - I think as we're ever going to see in our life time. And that would be, you know, we talk about, you put yourself out of a job, right? You want to put yourself out a job when you do this kind of work. You say one day there's going to be a day where I wake up and I'm not going to have to do this work anymore. (ORR piano theme music begins) It's not about science. It's about public health and it's about politics and at the very base of that it's about creating a world in which, you know, people feel like their lives are worth protecting. That's the work that we do here.

Coming up, the story of a man who knowingly put his life at risk with unprotected sex. We'll be back with more on our special AIDS These Days when Outright Radio continues...from PRI Public Radio International.

BREAK

You're listening to Outright Radio...from PRI, Public Radio International, I'm David Gilmore. You can contact us at [Comments@OutrightRadio.org](mailto:Comments@OutrightRadio.org) or call us toll-free at 866-OUTRADIO. That's 866-688-7234. (Do this every time)

Now back to our special on AIDS These Days...

Sam, the subject of our next story, is an educated and intelligent man. He is from the generation lost to AIDS. But with a more relaxed attitude about the disease, Sam took a risk that delivered some unexpected results...

A little warning for younger listeners, this story contains a clinical, but direct description of unsafe sexual practices. Here's Sam's story...

S: In 2001, I was a 51-year-old man. I had been in a relationship with another man for four years. It was a very good relationship. We loved each other very much. It also was an open relationship. We each had sexual encounters with other people. I got involved with someone who I had met the previous summer. Someone who I was very taken with. Kevin. My partner, Jim, knew about this. Jim was sensing that my involvement with Kevin was more -- becoming more emotional. And it was. In February 2001, our sex went to a level where we had what was clearly unsafe sex.

It was -- and for educational purposes I'll be specific...it was receptive anal intercourse without a condom. But without ejaculation. What had gone on in my mind and I don't believe I was dissimilar from most gay men at the time, is that after having gone through a couple of decades of -- becoming educated and becoming steadfast in not allowing myself to become infected, I let down my guard. I lost my fear of HIV. Back when we were watching our friends and loved ones die, we were afraid. We were afraid of it happening to us and so we were very strict about safe sex. Then when those friends and loved ones -- people stopped dying, presumably because of the advent of the medications, the newer medications, the fear of HIV subsided and that's when people started taking risks with their sex lives. And that's what was happening with me.

S: Subconsciously, I believe what was going on in my mind was something like this. If I were to become infected with HIV what would likely happen is that nothing would happen for probably ten years. This is even assuming that there is no medical advances, but just with the state of medical science as it was then, I carry the virus in me quasi-dormant for ten years and when it would start acting up then I would start taking the medications and put it at bay. And I was 50 at the time so that pretty much told me I don't have too much to worry about. I'm going to live a full long life anyway. So that's how the fear of HIV wasn't with me anymore. Now that's not what happened,

When I did get infected and it was with this man, Kevin. I had a very severe and very extreme reaction, I was hospitalized, I came very near death and I didn't get my ten years, I had to get on medication right away, I've been on medication ever since. I was very lucky to have survived the infection.

S: from what I can remember of it, because I was so sick. I had a fever of 107.3 and I was going into convulsions.

People were with me in the hospital. Were up with me all night. Holding me when I was convulsing, cleaning me when I was, messing myself. Just sitting with me and praying for me.

I had to have – I had people with me either family members or friends, someone with me 24 hours a day and every time – they would just hold me when I would go into this convulsion. It was just unbelievable. It was like being tortured and I remember it vividly and I had no control over it and I suffered a great deal of nerve damage, which I did eventually recover from. I had a paralyzed vocal cord.

When I came out of the hospital, I was in a walker, I'd lost 30 pounds and I wasn't overweight to begin with. So – and I had no voice, I spoke with what sounded like was a severe case of laryngitis so I looked, I looked very much like someone who was dying of AIDS as they looked like ten years before.

DG – You were just one month into the sero-conversion?

S: One month into it. I was still testing negative on the standard HIV antibody test. They confirmed that I actually had HIV from, from other tests.

DG – What was Jim's reaction to all of this?

S: after long sigh) It was very, very difficult. And this really, it damaged our relationship and it wasn't just the infection. It was me getting involved with Kevin. And it all came to a head with this. And, Jim and I have been spending the past two years seeing what we can rekindle between ourselves, between each other.

DG: And Kevin?

S: I haven't had contact with Kevin in over a year. He actually moved away and it was also very difficult for him.

DG – Did he feel a sense of responsibility for what happened?

S: – Well, sure. Sure he did.

DG – What I think was particularly shocking about it is that Kevin had no apparent signs of HIV. He was sort of youthful and beautiful and the minute that virus transferred over to your body, it wreaked havoc.

S: Right. A situation for which I have had no small degree of resentment. Sometimes feeling it towards Kevin, sometimes toward God. Why am I, Why did I have to react the way I did. But that's – This virus treats everyone differently. And in my case it was near lethal and certainly as damaging as it was to my physical body, the emotional recovery has been longer, slower and even more difficult.

DG – You were in critical care with a 107.3-degree fever for how long?

S: – I was in critical care for eight days. My fever, that's what it was at it's highest, that's what it was. They had to put me on ice to take my temperature down and I guess they ran a couple of CAT scans afterwards, after they did get it down, because they feared I might have suffered some brain damage. I apparently did not.

DG: We'll be the judge of that. (Laughter.)

Music

S: My life has become much more isolated and it has not been a fun ride. There are many people who have gotten infected who have been able to find some good in it, have been able to find some kind of gift to their life because of that. That hasn't happened to me yet. If there is a benefit to me from this infection, I have yet to find it.

Long Music break

DG: Certainly the gay community has benefited enormously from effective treatments for HIV/AIDS, yet over 16,000 deaths in the US were reported to the CDC in 2002. A declining number, but still significant. Now, when the anti-retrovirals fail to deliver healthy blood work, when someone with AIDS no longer can take care of himself and a terminal diagnosis has been delivered by a doctor, the end of the line is very likely to be an AIDS hospice.

In San Francisco, the AIDS hospice known as Matri was founded by Issan Dorsey, a legendary Zen Master and occasional drag queen who addressed the needs of the Castro neighborhood taking in men who were dying and caring for them. 19,000 people have died of AIDS in San Francisco since 1981, many of them at Matri.

This friendly institution marries modern health care, Buddhist philosophies and provides a community sanctuary for the dying and their attendant friends and families. I spoke with Tim Patriarca, the Executive Director of Matri to get a little bit of the history of the hospice and the changing profile of who arrives at their door with AIDS these days...

DG – Let me ask you about the numbers. Perhaps maybe ten years ago, fifteen years ago how many people were coming to Maitri every year and dying versus now.

TP – Well, the answer to that is probably quite telling. There weren't any statistics taken at the Hartford Street Zen Center because so many people died there. So there is no way of knowing. We estimate that since our founding in 1987 that over 500 people have passed away. So it's difficult to say. I wish I could give you a number. Here we'll see anywhere between 40-60 residents a year and again 80% or more will pass away here.

DG: I asked Tim what percentage of these are gay men?

TP- Well, it's interesting. We have traditionally served – the overwhelming majority of people we've served have been actually gay white men. Now we've seen a shift. We're still – we are majority gay men, but we are seeing more men of color come in and we're starting to see a shift to seeing more women and transgendered individuals. Where last year, I would have said that about 80% were gay men, this year we're looking at it, it's about 60%. So that's a serious shift in our demographics and we're going to be watching that to see if that will continue.

DG – And what about the ages?

TP Well, you know, traditionally when I started we saw people who were in their 40's and 50's and 60's and now we are starting unfortunately to see people who are younger. So we had our first individual in quite a long

time in their 20's here and we're seeing far more people in their 30's. So it's not a good shift and it's something that really worries me and it is one of the reasons that Maitri is trying to take an active role and especially talking to young queers and young gay men of color.

DG – How has care for people with AIDS changed from ten years ago now that we have protease inhibitors?

TP – Well, there's a couple ways to answer that. One – the care that we provide has remained the same and the care basically is wonderful staff that has been dedicated and working at Maitri in many cases for 15 years and surrounded by people, volunteers who dedicate a lot of time to just surround people with love and compassion. So that hasn't changed. But what has changed is the medical portion. We're seeing sicker people who are here for a longer period of time. So at the beginning we were purely a hospice facility, treating those at the end of their life and in most cases at the very end of their life. And now, we have a multi-faceted program. We're still-- the majority of people who come in here, around 80%, die within our walls, but we also do a couple of other programs. Transitional Support. So people who have an acute period of their illness or just found out about their illness and they need to get stronger, learn how to take medications, learn how to live with HIV and AIDS. And also another population are those who are seriously debilitated with AIDS. So in some cases they were caught with the onset of HIV medications and they may be sight impaired or have serious dementia and we'll do a longer-term care for those individuals.

DG: Tim goes on the speaking circuit on behalf of the hospice for shock value, especially to young gay men...to let them know that there's a facility in their neighborhood that is taking care of the dying. He spoke of some of the challenges of that moving target of AIDS prevention...

TP: and it's frustrating. New things come up like this crystal use. Speed use. I think that this a major problem right now that we really need to discuss as a gay community and...but we are all very hesitant because it's not something that we want to put out there as a major problem, but we have to start facing these very difficult questions as a community and start taking care of these problems on our own and I think there's a lot of things we have to face up to.

DG – Do you find a lot of people coming here who are addicted to crystal?

TP – We have people who are addicts or former addicts, certainly. Yes. We have a number of individuals who come in every year who have had a substance problem, substance abuse problem. As well as a number of people who for a number of reasons haven't had a stable home in quite a long time, which you know, if you don't have food on your plate and you don't have a stable shelter, it's very hard to expect someone to comply with a confusing and difficult number of medications and schedule of medications each day. So it's also a problem we needed to talk about as a city, as a state, as a country about dealing with the things in terms of not just putting money into prevention or into care, but also looking at this greater problem of drug abuse and homelessness and substance abuse.

DG – Let me ask you a tough question. Do you think? Could you go out on a limb and say that there is a predictable track of behavior, that once you start doing crystal, that the end of that line of the addiction to crystal is going to be being here at your doorstep?

TP – That is a difficult question and – but, I will say that I am very, very anti-crystal and I think that it is so damaging our community that I do think that it ultimately leads to very risky behavior, sexually. And, so many of our friends in the gay community, that we personally know, people we know that you never would expect to fall into addiction, but crystal is such an evil drug, I do think that if people use it they are going to not only HIV we are seeing an increase in syphilis in the city and it just adds to this problem. I do, I do think it's something that is such an issue for San Francisco and I think each urban area right now.

## Music

Mary Ellen Mullen who is the Program Director gives us a quick tour of the facility at Maitri. Considering that essentially, people come here to die, it's surprisingly cheery when you walk in, and for me, having had 2 friends die here, it was in a way like returning home. ...I met Mary Ellen at the top of the stairs in the foyer.

MEM: So we have 15 private rooms here. And they're all lined up on an L here. The rooms go up and down this hallway and I can take you into our meditation room first. We have this room as kind of a quiet place for people to come – friends, family, certainly residents, staff. Just to take a little time out. Everything you see is donated from various groups. So it's kind of a special quiet space.

MEM: So we'll walk down the hallways here. I'll show you an empty room – let's go right here, David. This is a typical room here at Maitri, although we haven't got it set up yet, we have someone moving into this room on Wednesday. Each room has a private phone, CD player, and a TV with cable. People come and they're here for various lengths of stay depending on why they're here and they pay 60% of their income for all the services and for rent. So, we'll go walk down the hallway to the other rooms.

So there's our nursing station where we deliver an incredible number of meds every day. I can ask the LVN if you want a number. OK? (knocks on window) This is Sabrina and she's one of our LVNs who's been here since we opened over here on Duboce St. Sabrina, this is David. And I was just going to try and quote him the number of meds you pass a day. Sabrina: Let's see...there's probably more than...in a 24 hour period...there's probably anywhere between 300 and 500 pills a day.

DG: Mary Ellen leads me outside to a patio off one of the hallways. A small fountain is trickling water...

MEM: Now this is the side where we get the most action – the smoking patio. This is where a lot of our residents hang out. And I always call it our informal support group because the residents are incredibly supportive of one another – I've never seen anything quite like it – from all walks of life they get together and really support one another around their illnesses. So we also have a mini-version of the larger fountain next door – with the same “loving kindness” message.

DG: The inscription on the fountain in the patio reads:

May all beings be well and happy  
May all beings be harmonious and peaceful  
May all have the light, the way out of suffering, the way home  
May we each share our bright wondrous nature for the benefit of all  
beings

Mary Ellen then leads me back to the foyer where there sits a small table with candles and a journal with writings and pictures pasted to the parchment pages..

MEM: And this is where we have our memorial table. So when a resident dies here at Maitri, we let residents know – family, friends, obviously. And then as a way of notifying the rest of the community, and in memorial, too, we light a candle here and then we put an individual's name in the book and then people can sign little notes to them. So it's an important part of what we do. DG: It appears that someone just died 2 weeks ago.

MEM: Yeah, that's true.

## Music

DG: After my tour of the hospice I found my way to the exit... down the big staircase with a painted image of a tree growing up the walls. With each step, I thought about the 36 million cases of HIV/AIDS, worldwide...I thought about the million people living in America with the disease and the 17,000 new infections each year in the gay community... and I found myself asking the question, "What will it take?? What will it take for us to end this disease?" In the 90's we thought we had the answer: Safe sex information and supplies – a condom every time. Well that strategy didn't outlast the virus. Then when the anti-virals arrived, we all thought AIDS was becoming a manageable disease. The sixty people who die each year at Maitri would certainly argue that notion.

Some of us dream of a time when there is a cure for AIDS while some still dream of a time when AIDS cures homosexuality. It seems to me, that if the burden of prevention is to rest on the shoulders of the gay community, then first we must learn to respect ourselves. How can we as gay folks protect a life that has been so severely devalued by hatred and fear?

Music

Before leaving I took note of the inscription above the archway written by Issan Dorsey, Matri's founder, who died of AIDS himself in 1990. It reads: "We have bonds with each other that are more important than life or death."

Music

That's all for today's show.

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