

“HIV in My Day” – Interview 5

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Interviewee: Paul Harris (PH); Interviewer: Ben Klassen (BK)

Ben Klassen: Alright. Thank you so much for agreeing to participate in our study and for sharing your story and experiences with us. We’re really excited to hear your experience of the first decade of the epidemic. We like to start these interviews by asking people how they first became involved in the community – the gay community, that is. So, when did you – yeah, when did you first come into the gay community or start engaging in gay life?

Paul Harris: I came out, I guess, when I was fourteen, which would have been 1967 – sort of... made my first steps anyway – and then, I guess, was fully, uh, propelled into the gay community when I was in university, and that was in 1973. And from then on, it was just gay, gay, gay. [laughs]

BK: So where were you going to university when you were coming out into the community in a more formal manner?

PH: I was going to York University in Toronto, studying theatre, which made it very easy to come out... [laughs] ‘cause half the boys were gay, so that’s probably part of the reason why I was attracted to it.

BK: And it made for an easy transition into the community.

PH: Made for an easy – yeah. Made a – I got a community, and then... yes. I had a community and then I came out.

BK: And what did the – what did that community look like?

PH: Hmm... well... What did gay look like in 1973? It was... not that much different from today. Perhaps, maybe a little less... self-confident but generally speaking, the – we were past the stage of being hidden. People were comfortable with being gay and – and we did still tend to flock together. And it was – people were very – very much the same as they are today. I don’t know how else to answer that.

BK: Yeah, it’s kind of a meaty question in a way. Anything else you can say about what the community looked like, I guess, prior to the epidemic?

PH: Ah, well... Much more bar-oriented than it is today, because of the lack of – or the impact of the social apps. Sex was – sex was the still the binding ingredient in the gay community, and I think that because – because HIV hadn’t come about yet, there was less of a sense of... It wasn’t – it was not as socially acceptable but it was a lot less ominous, so sex was a bit freer. Not necessarily more frequent or less frequent, but more psychologically free.

BK: And you – so you came to Vancouver in?

PH: 1983.

BK: What did the community look like – I mean, I know I’m kind of asking the same question over...

PH: And over again.

BK: But is there anything you can say about Vancouver’s community at the time when you moved here?

PH: Um...

BK: Anything that stands out?

PH: Not much that stands out. The difference was – it’s hard to know the difference between me – the difference between being twenty-four or twenty-seven and the difference being sixty-three. So, when I was twenty-seven, everyone was having a lot of fun, but was that because I was twenty-seven or because people were having a lot more fun. You know, the bars seemed to be a lot more fun. There were a lot more of them. There were, uh, there was the Play Pen South, so there were sex clubs in Vancouver and – and everything looked... everything looked – very... there was a lot of hope for the future. But then that could be because I was twenty-seven.
[laughs]

BK: And so... I guess, this is a bit of a rough transition, but when did you first hear about HIV and AIDS?

PH: It was probably in – I always... What I remember is, the first time I remember hearing about it in an identifiable way, as opposed to reading articles about GRID in the newspaper, was – I was living in Calgary at the time. It was 19... probably 1981, and one of the guys I knew – gay – said, as a joke, “What does GAY stand for?”

And the answer is “Got AIDS yet?”

And that’s the first time I remember – the first thing that sticks in my mind as the first time I remember AIDS sticking in – or becoming part of the popular discourse.

BK: And so – after that point, where were you learning about the epidemic, or – what kind of sources of knowledge or information were there available to you at the time?

PH: I think... At that point, it was all newspaper and, um, there wasn’t a lot of – I don’t remember a lot of discussion about what it meant or what the impact was. I think that... I think that, from what I recall, it wasn’t until probably 1984 or 1985 that it started having a real impact, at least that I saw, in... in the gay community. By the time, I was here, and I remember when I moved here, there wasn’t a lot of – it certainly hadn’t impacted people’s behaviour. It didn’t seem to enter into people’s consciousness. It would have been... The first time I remember is

when everyone started – when HIV testing became available, which would have been probably 1985, 1986. Going for my first HIV test and then everyone I knew going for their test, and then finding out whether they are positive or negative. And, at that point, everyone knew what the outcome of having a positive HIV test was – which is, you have to get your affairs in order because you’re going to die soon.

BK: Hm. So, there wasn’t this immediate – when the... when there was this first information coming out, there wasn’t necessarily an immediate sense that this was happening here, or that was... you know...

PH: It wasn’t – it wasn’t happening to me. I think that... I think that my understanding or my experience of human nature is it doesn’t really make an impact until it starts happening to you or to me, and it didn’t start happening to me until it started impacting my life, which is when the... The emotional baggage or the emotional fear came, and how that – how that started to impact my life and the lives of the people around me and... And that’s when... That’s when the epidemic started happening for me.

BK: So, how did it kind of start... How did the epidemic start manifesting in the community? What did that look like in the beginning?

PH: I think... What did it look like? I think it looked like... fear. I think that people began to understand that this was going to be something that was going to impact everyone’s lives. Started to... people started to get tested... Friends that I knew were HIV positive... It began – just trying to remember the timeline... By 198... by 1984, it was – it began to be a crisis in people’s lives.

I – that was the year that I decided to go into nursing school and that was... I thought I had to be part of the solution. I had to do something about this. As people began to get sick, friends began to get sick, and... I didn’t know what to do. I – so, thought that becoming a nurse would be... the best possible solution as far as doing something about the epidemic.

BK: So, that was very much a decision made in light of what was going on in the community and within your more immediate community?

PH: It was. *It was*. I became... decided to become a nurse because of HIV and how it impacted the people I loved and my community.

BK: Wow... [pause] When you were getting involved in that more formal form of caregiving, what did the medical respon– like the early medical response to the epidemic look like?

PH: I... I don’t remember. I mean I remember – I remember we... I remember going to the doctor, going to the doctor, I remember friends going to the doctor. I remember going to the Bute Street clinic and getting tested. My first formal introduction into AIDS care was when I was a student – I worked in St. Paul’s hospital – and... It – I think... people talk a lot about how AIDS care has changed. I remember you had to – had to gown in order to go into someone’s room, and... I think people often see that as a type of stigma and I think it’s – it is... it’s an intersection between stigma and policy. So, the hospital had a policy because they weren’t... they wanted

to... How HIV was passed was still – there was still some question, though not a lot, but there was still some question – so the policy was that people had to gown when they went into someone’s room.

And, of course, what the impact of that is that people didn’t go into rooms because they didn’t want to put on gowns, so there was that sense of isolation. And I remember... I remember when a friend of mine was a patient and I was a student, and... I remember people not going in – everyone going into his room and having to gown. Now, his friends still rallied around, but it – um, there was still that idea that you had to... Somebody had to bring his tray – his lunch tray, his meal trays – because they would sit out in the hallway, ‘cause no one – people would forget to bring them in. And that’s – those were the days when... It was different than it is today.

BK: And, when you were becoming involved in nursing, was that already beginning to shift quite a bit?

PH: It – uh, yes. By the time I – by the time 1987 rolled around I think things were a lot more normalized. People... HIV care was – it was still, there was still a lot of stigma around HIV, but I think that the actual medical care had settled down. So, I think that St. Paul’s did a – and health care in general – within a few years, it just became one other problem, not handled any differently than anything else.

Still, the problem is that there was no cure and there was no – there were very few effective treatments – which made things really difficult for... for... emotionally difficult.

BK: And that kind of thinking... Thinking about that early medical response, was that mostly just something that came out of a space of fear from the perspective of the medical establishment, for lack of a better phrase?

PH: Um...

BK: Or was that something else?

PH: Caution. Fear. I mean... they are all different words for the same thing. I mean... I think that it was... If you think about in terms of the employer or the community – or the people in charge – part of their job is to make sure that everyone is safe, so I think that there... People were overly cautious in retrospect, but... and I think that it had very difficult...

And the community had to fight, or struggle to – to change attitudes to HIV... But I think that, as attitudes changed, the medical knowledge also evolved at the same time.

BK: Yeah, absolutely. Yes... So, when you started working at St. Paul’s, what did that role – can you take us inside what that... what that looked like for you, as a nurse working at St. Paul’s?

PH: Well, I worked on the medical floor, so the... The medical floors were where most people – at that time – where most people with HIV were admitted. And... it... I don’t know. It’s a series of stories. So, what did it look like?

It was – it was difficult. It was emotionally traumatic. People... people died. People got really sick. Um... It was – it was hard for the family. The people were sick and they stayed sick for a long time and – and... And terrible things happened. I mean, HIV was a terrible way to die. And when they – when it happened they... The people who died were young. They were in their twenties and thirties, and they weren't supposed to die, and they weren't prepared to die, and their families weren't prepared, and their loved ones weren't prepared, and... And it just kept happening and happening and happening.

And I'm sure that everyone who tells this story will tell the story about how in the eighties and the early nineties, all it was was this series of funerals that we went to. And... at work it was... It was taking care of people who were really sick and who weren't going to get better, who you were young, and who you may have known or cared about, and... And just trying to get through it.

BK: [Pause] I think we... We kind of, for this study – for the purpose of this study – we've drawn this line between a formal caregiving role and an informal caregiving role, but just hearing you talk about that, that sounds like a superficial distinction.

PH: Well... If you had a... If you had a partner who was dying of HIV, is that the formal or the informal? You were the caregiver. And if you were working in the hospital, I mean, it's true... I mean, but if you were part of the community, it's just a – it's just a continuum of care. So, I took care of people who were dying of HIV when I was at work and I took care of them when I wasn't at work.

The difference is... There is a difference, but it's – it's just a – it is a, right – it's partly artificial. We – I think we all... Some people were kind of lucky enough to have it not have it deeply impact their personal lives, but most people in the community, it was – it was something that you dealt with on a daily basis.

And, just like anything else, some people chose to jump in, and do someth– to fight – and some people chose to sort of deal with it in a different way. And sometimes you didn't have a choice.

BK: Yeah, it's been - it's been interesting talking to a few people now and we've really seen that spectrum of responses where some people absolutely jumped in and some people responded in another way that kind of diverges from that, so... If we were to try to talk about generally what was going on in the community in terms of the response from the community, what did you witness or see there? How was the gay community responding to the epidemic as it was escalating in the mid-eighties?

PH: Well, that's when AIDS Vancouver started. That was a response of the community. I mean, there's a lot of... There was, I mean... it's just... So, there was Loving Spoonful, there was Doctor Peter, there was – there were a multitude of ways people got involved. People got involved on a personal level. People got involved on a community level. People gave money, people gave time...

Back in the day, of course, the – gay women, lesbians were a backbone of the response. One of the reasons, I've always felt, was because gay men were dealing with it on a... often on a very personal level, emotionally overwhelming, and the lesbian community came together as a... As a group that could emotionally handle the – sort of the organizational parts.

I remember... I remember I went to one of the early board meetings of AIDS Vancouver and just feeling like the work that had to be done. I wasn't – I didn't have the emotional strength to carry that on. I was – I felt like I was doing all I could just to hold it together.

BK: Yeah, I mean it sounds like you were – you were maxed out.

PH: I *felt* like I was maxed out. I think that that's how most people – most people I knew felt that way, regardless of what they were doing. It was... That was the crisis part of the gay men's health crisis, and I think we were all – one way or another – in crisis.

BK: And so, you didn't become involved in any of those organizations?

PH: I didn't. I... I didn't. I was there for some early organizational meetings of AIDS Vancouver, but that's... The rest... The rest of my memories are all personal. Taking care of people – at work and at home.

BK: What was AIDS Vancouver doing at the time? You mentioned the support – a lot of support to people who were living with HIV.

PH: I think... Yeah. I think AIDS Vancouver – this of course was when – they were doing a lot of public awareness and... Trying to change public policy and health policy around HIV and the response to HIV, so they sort of... Yeah.

BK: Do you feel like that information was getting out there? Sorry, not so much around policy change, but around education and information within the community?

PH: I think – I think it – I think we, from the level of, here in Vancouver and internationally, I think AIDS service organizations really came into the fore. They did a lot of work and I think it was very successful. People... people knew what was going on. They understood... I think that... The idea of safer sex education and support for people with HIV, that was – that was what they did, and I think they did a very good job.

BK: Do you have any thoughts on what made them successful or...? I mean, I know this is getting... I know this isn't what you were doing at the time, but just as somebody who was observing those ASOs, what were they doing that made them successful?

PH: I think... They... What were they doing? They were getting the information out and they had – they didn't have to spend a lot of time motivating people because the – it was the health crisis that was motivating people to... to hold onto the information that they were providing. I think that getting condoms and getting the information around how HIV is transmitted was...

They did – I think they did an amazing job to get that information out and I think they had a very – generally speaking – a very willing and motivated audience.

BK: People were very much seeking out information. People within the community I guess.

PH: Yes. Our lives depended on it. And I think that everyone – I think that that’s the thing that, if you will, helped, because everyone understood – everyone saw everyday what the impact of the HIV epidemic was. It wasn’t hidden. You saw it when you walked down the street.

BK: Just to touch on something that you touched on earlier – just a couple minutes ago – you mentioned the involvement of lesbians within these organizations and within the response in general. Did the relationship between gay men and lesbian change as a result of the epidemic, do you feel?

PH: I think that prior to the epidemic, there wasn’t a lot of – I don’t recall at least – a lot of social crossover. We were separate communities and I think it was HIV that made us realize that we were the same – we were in the same community.

BK: That’s super interesting... Shifting gears a little bit – I think we can come back to a lot of these things but... So how was your... As you were kind of encountering information about the epidemic, maybe through ASOs and through school and all these things, was your personal behaviour changing a lot in response to this information, or not so much?

PH: I think... In different ways, it did have a big impact. I think that, like a lot... As I’m fond of saying, people stopped having sex – not all sex but I think there was a chill around gay men’s sexual practices. Maybe not for everyone but... When... I remember what I – my perception is that people stopped having anal sex. Now clearly it’s not true, but I think that – that was the effect for me. The other – one of the things that makes it difficult is that, at the time, I was in a relationship, so the... That changed my behaviour for a different reason.

I think that... And I think that, just on an emotional level, I think that because people were in crisis, I think that that also changed our behaviour. When – when the world is coming to an end, you can either eat, drink, and be merry for tomorrow we may die, or you can allow it to... make you depressed, and I think that there – I think people responded in a variety of ways.

I got depressed. I was not the eat, drink, and be merry type. I think that that was – that was something that I was very aware of around me, that people responded differently and that... I felt... a tremendous burden in the sense that there was... There was something terrible happening every day and it made it more and more difficult to keep going.

BK: Hm. Did – did a consensus emerge within the community that centred around safer sex as, like, a solution to this? Not that emotional shift that you’re alluding to but the fear around sex?

PH: Yes, I think that... My perception is that the consensus was that safer sex – safe sex – was the way to go. That’s how... That’s how people responded and that if... And I think that, in a sense, part of the reason why the implication that if you weren’t practicing safe sex, that that was

something that could be... You could get shamed – you could get publicly or privately shamed over – so that if you weren't practicing safe sex, this was something you were doing that was wrong. And I think that that's a reflection of how safe sex became a – not only was it a health practice, it became an ethical and moral practice as well.

BK: Hmm, that's very interesting. How did you – thinking about the immense emotional burden that you're talking about – how did you avoid burning out or just, I mean, collapsing under the weight of all of that?

PH: You know... I think people – I don't think we have the option. We didn't – I didn't have the option of burning out or collapsing. It's not that I wasn't burnt out – I was – and it's not that I didn't collapse. It's that even though you did burn out, you still had to continue. There was no out. There's no... there's no escape. There's no "I resign from this," because it's not just a job, it's people – it's your life. You can't... you can't not... there was no... There was no "No."

It's like when there's a war going on. You can't, you know, call someone up and say "I think I'd rather not be here. I'm leaving." There's no way to leave.

And that's the thing that... That's the thing about the... That's why they talk about trauma. There was – it wasn't... We couldn't escape. We just had to keep going and to... When you're in that situation, just like any other situation where you can't escape, then you just have to take that damage and – keep going regardless. And that's why people would internalize. That's why... They talk about how – how do we respond to trauma? How do we respond to that pain? And that's why chemical dependency happens. That's why displacement behaviours happen. That's why people get depressed. But even when you're depressed, even when you're drinking too much, you still have to continue. That's why people turned to these other behaviours. It's because you, uh, have no choice. You have to go on. You have to deal with the pain somehow. And I think that that's what it was like for people.

BK: And we still see that to some extent – the aftereffects of this.

PH: There is an echo from HIV in the community. I think that... We talk about the trauma of living in a heteronormative society, how we are all traumatized when we are young. I think that's also true. But I think... There's a million different ways to become traumatized and what happened during the AIDS crisis is that we just took on another form of trauma and we just kept – some, I think most people didn't have the option of... of resolving the trauma, if in fact... What is the resolution of trauma? I don't know. Love, I guess.

BK: Yeah, I mean, from what I know of the epidemic, one of the things that always stands out to me is this conc- - this idea of resiliency, but that's not quite the same thing as what you're articulating, I don't think, right? I mean, there is an element of that?

PH: Resilience. Are we a resil-... Well, I guess it all comes down to how you feel about, or what your response is to the – the assertion that "that which does not kill us, makes us stronger." Um... Some would agree with that. I'm of the personal opinion that that which does not kill us often just cripples us. It's true, if you're crippled, if you don't have legs, your arms get stronger

because you have to compensate, but the idea that being made stronger is actually a good thing is not necessarily the case. So, I don't...

Even though there are positive outcomes to the HIV crisis, I don't – I don't see it in any way as a positive thing. And... I think that a lot of the resilience... How shall I put it? I think resilience – I often think of resilience as, um, you spring back like a foam cushion. The cushion is not damaged by the fact that it has been crushed. I don't see human resilience in the same way. I see resilience as you respond in the best way you can. And sometimes we respond successfully, and sometimes we don't. But there – there's always a cost.

BK: Yeah, I think that's... I mean that's certainly something we want to talk about with everyone we're talking to is, on a grand scale, how did this impact the community? And you alluded to some positive outcomes – and I don't want to just focus on those – but what might have some of those positive outcomes been?

PH: Well, I think – I think it was – I think HIV made being gay political. It was a political act. So, even though coming out before HIV was something that people did, I think when HIV came along, it now became not only political but moral, so that people felt that they had a moral duty to come together as a community and to fight because of the... Because there was a huge sense that the society wasn't responding, and we had to respond – we had to respond on a personal level, to take care of ourselves, but we also had to respond in order to move society towards being more compassionate and caring for us and for others as well. And I think that that's what gave – that's what I believe gave the gay community the moral high ground that it has tried to maintain since.

BK: So that sense of the community, in some ways, coming together, but also as like a political entity, I guess.

PH: Yes. We – we came together as a political act, as a social act. It developed community, it created community, and it also... It gave purpose... and... and meaning. Which is... it's something that... I think it's something that's a lot more important than we recognize, that having meaning and purpose for a person or a community is very important, and as... As we move forward as a community, I think we have to keep in mind that we need to keep that purpose in our – or keep a purpose.

BK: And so, for you personally, the epidemic did give you – I mean clearly...

PH: I think... I think that that's what happened, is that the... HIV was the gay men's health crisis. We owned it. It's not true that it only happened to gay men, but that became the defining moment for the gay community... and... For twenty years, it, um, it became the point – the intersection point for our community. And, you know, you think of even today, the funding for a lot of gay – for a lot of gay community organizations – comes from money set aside for dealing with HIV. And since we are in what they call the "post-AIDS era," I wonder how that will impact this in the future.

BK: Kind of related to this, can you articulate how HIV and AIDS changed the way that you related to the gay community? I mean, did it? Or... did it draw you in in a way that you...? I mean, it sounds like you were pretty involved in the community before this too.

PH: I think I was gay and I think I was involved in the community in the sense that going to bars makes you involved in the gay community, but I think that HIV created an idea that... there was a community, of which I was a part of, and that we were working together towards a common goal. I – when you ask – that’s why earlier in the conversation when you asked, “What was it like to be part of – what was the gay community like?” I don’t have a... I wasn’t conscious of being part of the gay community. I was conscious of being gay. My sense of becoming part of a community arose out of my response to the – HIV – and the community’s response to HIV. They – they happened together. I responded and the community responded, and that brought me into a sense of community, as opposed to just hanging out with a bunch of guys.

BK: I mean, those are pretty profound positive impacts. Anything else spring to mind in terms of thinking about positive impacts of the epidemic on the community.

PH: I – that’s what... I think that sense of purpose, creating a community, common goals... I think that’s what community is. And other profound impacts... Well, anger. It’s a great motivator for – for... It gives you a lot of energy and people were really angry. You can either focus that anger outwards or inwards. I think there was a lot of anger focused outwards. That’s what motivated people. That’s what got them going.

BK: What did some of that outward channeling of anger look like? How did it manifest?

PH: Well, I mean, that’s where... Later on, where... Later on from what I’m thinking of is the whole – the movements around ACT UP where we fought, where we actually went out. Civil disobedience. I think that that’s one of the ways that the anger manifested itself... And though... I think that though Pride, like Pride marches, were happening before the... HIV – I think it was partly that that caused people to – to make a statement. I remember early – early, whenever early was – the early marches, it wasn’t the same as it is today. People – there weren’t people flocking to watch the parade, and marching in the parade was – it was a statement. It was an act of defiance, which of course is not what it is today. Now it’s about being a realtor. [laughs]

BK: Yeah, it is – it’s very commercial, isn’t it. It’s – having looked at images of the Pride marches in the eighties and early nineties, I mean, ASOs always had a huge platform or were very strongly, or heavily involved in a lot of Pride marches. And I don’t even know if most community organizations have a presence in them anymore. [laughs]

PH: Yes. Yeah. Times have changed.

BK: Were you involved in any of those activist channels?

PH: No, not – not overtly. As I say, I... my response was not one of anger. I turned that anger inwards.

BK: But as an outsider looking at those – like ACT UP, for instance – you saw that this as something necessary, or...?

PH: Yes. Absolutely. I think that... At the time, and certainly now, I think of there's things that I can do and there's things that I can't. There's things that I find I'm capable of, so... Public unrest has never been my strong point, so though I admired people who could do that, and I supported them emotionally and financially, I wasn't able to do that myself – or at least I didn't feel I was able to.

BK: What were... Well, I guess, what was the governmental response like, because I think that's what ACT UP was largely responding to? What did that look like? What was...?

PH: I think... Not being part of the government, I think we viewed it as non-benign neglect, so I think that there was a sense that we were abandoned... And that's what... I mean, I remember that thing that's often quoted that Ronald Reagan never – didn't mention HIV or AIDS. I think that it was not something that was on the... It wasn't an issue that rose above pure healthcare until the gay community and ACT UP, or ACT UP-like organizations, made it an issue.

BK: We hear a lot of people talk about the Vander Zalm government in particular when it comes to this topic. Any kind of thoughts or memories of what that governmental response looked like?

PH: I... All I remember is having very low expectations and having my low expectations met every time by the Vander Zalm government... So, I don't... I just remember feeling the same way as everyone else felt, is that there was not – there was no political will to champion the cause.

BK: And so, the only people who could really force the issue were people within the community.

PH: I think that we – we may have had allies, I'm sure we had allies, but what we... But making it a political... Making it a political issue, making it an issue that was discussed... I think it took a lot of energy for people to actually get that response that we were looking for. I think that... Yeah, as... I don't have enough information to know how much the – how much our success at making it a political issue actually changed the course of HIV care and the course of the disease. However, I mean you can see – at least I can see today – the way... the way political organizations deal with other problems, like our current overdose epidemic, and how the idea that something that is a medical problem becomes a societal problem. I think that arose out of, um, the work that ASOs did at making – making health a political issue.

BK: Yeah, highlighting how health is really socially determined in a lot of ways. That's absolutely a profound impact of the response, I think, to HIV and AIDS. Um... taking one step further back, we've talked a little bit about how medicine was responding. We talked a little about the governmental response and also about what was going on in the community, obviously. But what was going on in mainstream society? What was being said or do you have any, again, memories of what that looked like?

PH: Um... My memories are... What do I remember? I remember when Rock Hudson died and I remember that, in retrospect, it's often said that that's when HIV hit the public consciousness. And I remember when Rock Hudson died, and it had been so – at that point, it had become so much a part of my daily life, it – I missed that. I didn't... I didn't realize that this was the first time there was a public discourse on HIV, because it was part of my public discourse, it had been for so long. So, I think that... I think, in a sense, I don't remember. What I remember is my life and I'm not really good at remembering what other people's lives were like. I don't remember what society was doing. I just remember... I remember when Rock Hudson died, it was like, wow, that's just another one whose died. It was just one more in a list of hundreds... thousands, but it was hundreds of people that I knew.

BK: I mean, that makes complete sense. If your whole life is absorbed in a very personal way, you don't – you're not paying attention – you don't have time to pay attention... or energy.

PH: I – it's not... I don't... I think... I don't know what it's like for other people – you probably have a better idea than I do – but what I remember is so much... It may not be what I knew at the time but what I remember is different. What I remember is... I remember at that point, it was... it was so normal. It was so... mundane. HIV had be – and death – had become such a part of my – not just mine but everyone I knew's daily experience that it was... And I think that that... I think it was a shock – or it would have been and it is a shock – to think that at that time it had not hit people's consciousness.

And certainly, the people I knew, and the people I knew who weren't gay but, I mean, because I was gay, you know, I remember then everyone was thinking, well, wondering whether I have HIV. “Do you have HIV? Are you alright?”

And... So that, for me that was the signal that it had reached – it had reached the world around me because everyone I knew was either worried about themselves, or the people that knew them were worried about them. Well... this is... this is certainly... it was... It was the war that I thought it was. It wasn't like... it wasn't like the war was happening and no one was noticing, because everyone in my world noticed. And that's why when... when it hadn't hit someone, when the war wasn't effecting someone else, it wouldn't be something that I remember, because it wouldn't be something that I would understand.

BK: Yeah, I guess, part of what we're prying at there is how did this intersect with experiences of homophobia or...? But that's not really something that you were so... involved that it was...

PH: I guess I've always been lucky, or I've... I've always immersed myself. So, I lived in what used to be called the ghetto. I worked in professions that were dominated by, if you're a man – like when I was a nurse, it's not true that every male nurse was gay, but a fair number were. It's not true that every man working in the theatre was gay, but a fair number were. I... there was – I arranged my life so that there wasn't a lot – I wasn't exposed to a lot of coming out issues or homophobia. Not that it didn't exist, it's that... Just, I was out. I was out in the sense that going into the closet wasn't really an option for me, or at least that's how I saw it.

BK: Sounds like you chose very well in a lot of ways.

PH: Well, I... I often think that because I'm essentially a coward, I had to do something that made it so that I didn't have to make the choice, because if I were faced with making the choice of coming out every day, it would be overwhelming. So, I just made the choice to come out once and stay out.

BK: Kind of relatedly, but not quite the same, did you see stigma around – like, was there stigma around HIV at the time? I mean, you certainly would have seen that...?

PH: I guess the question is, *at the time*, because stigma around HIV has evolved... So, in like 1985 what did it look like? In 1995, what did it look like? And what did it look like in 2005? I mean, in 1985, stigma around HIV was... I remember... What I remember is: was it alright to kiss someone who had HIV? Can you share an ice cream cone with someone who has HIV? I remember those being questions in 1985. In 1995, I remember then that there were questions that other people had, but I don't remember having – I don't remember asking the question. And in 2005, I remember those questions still happened but a lot less often and not usually from people within the gay community.

So, I think that... Now, that's not a measure of stigma. How socially isolated was someone who had HIV? I remember when in 1985, it was difficult. People weren't very comfortable with taking care of someone with HIV. That is to say, you know... I remember my friend. He was... he had HIV. He died in 1987. By 1986, he required, uh, home, like... someone to take care of him at home. I remember that not everyone... not everyone was willing wanted to do it. So, you know, taking someone to the bathroom, it's like, "I don't... I don't know if I feel safe."

And... And then, in... ten years later, there was still stigma around HIV, but it was, I think that it became more social, so that people with HIV felt isolated. I think it's hard to... it's hard to tease out the fact that in 1985, people with HIV were dying. By the time... by the time 1996 rolled around and the cocktail came out, people were... the evolution had started. As I recall, we're really talking about the decade, really, from the identification of HIV until the cocktail is the part that... what we're looking at in this discussion, so... But even in those ten years, things changed, and I think that that... there was a learning curve for the gay community and there was a learning curve for society in general. Obviously, the gay community learned a lot faster because we had to, you know.

But the stigma around HIV... I think... yes... I mean, I remember Dr. Peter. I remember – actually you would remember – you *know*... you know because it's your job to know when that was – but I remember how that was, in a local sense, that's when HIV went from being something that was within the community to something that was broadly, you know, became part of Vancouver, or it became part of Vancouver's response. And... and I think, if you've – if I were to characterize Dr. Peter and his video essays as being a way of putting a human face – humanizing HIV. I mean that was – that was something that happened by virtue of the fact that I knew and loved people who had HIV and were dying of HIV, or had died from HIV. So...

So... I don't know... Stigma. It was, I mean... It was, but it still is. It's just changed.

BK: So much of combatting that seemed to be about humanizing things and I know that there was a lot of efforts that went on within the community, especially early on, to humanize the epidemic.

PH: Yeah, I think... I think... yes, yes. It was... for me it was always human because I always say, you couldn't walk down the street without seeing someone you knew – if you didn't know them well, you knew them well enough – who was... I remember... I remember when the guy from Wreck Beach, who was one of the gay gods – like, he was beautiful; he was amazing – and then seeing him the next summer walking down the street with a cane. You know, weighing a hundred pounds less. To me... is... To me that was humanization because that was someone... that was seeing the impact on someone. Now... For me, the fact that it was happening to someone I cared about or knew, I don't... I don't remember whether... if it wasn't human before, whether that would have been enough, but it was. It was happening everywhere to – to everyone I knew, so I don't know. I don't know what it would have taken to make it human for me if I hadn't been surrounded by it.

BK: So, when you... Just to kind of return to your caregiving role – and you can just direct me as to how much you want to go into this, because I understand that this is traumatic, absolutely – but one thing I'm a little bit curious about is, when you were at St. Paul's, was there this... As the epidemiology of the epidemic shifted, was that really easy to perceive as someone who is on the ground at St. Paul's, you know, working with people who had HIV.

PH: What do you mean by epidemiology? You mean who was getting HIV?

BK: Like, as, I guess... partially as, you know, as it wasn't just gay men. As especially other marginalized communities began to, uh, show up more in the epidemic. Was that something that was really easy to see at St. Paul's or...?

PH: It... By the time, I mean... By the time it was noticeable, which would have been... I mean, how should I put it? By the time I noticed it, I wasn't working at St. Paul's anymore... So for what my memory is, is from that... My experience of working at St. Paul's is when... virtually everyone who had HIV was gay. Now... I don't know if that's true, but that's what I remember.

BK: And when did you move on from St. Paul's?

PH: I... [19]97.

BK: What did it look like when the cocktail emerged? How did that show up, I guess, in your health care provision role?

PH: Well, by that time, I was working in the community doing HIV prevention, so my... My perception of the cocktail is... I mean I have a personal connection, but professionally it looked like... What it was like giving someone an HIV diagnosis and what it was like, so... What the person's response to finding out they had HIV and... what information I could offer them, and also, of course, the big impact – or what I believe is – the impact of having a cocktail and how that impacted sexual behaviour in the gay community. It began to very... it's a lot more clinical

from that point of view. And typically, telling someone they have HIV – when I started doing HIV and telling them they’re HIV positive, their response in 1997 was a lot different than it was in 2017, because, even though it wasn’t true, by 1997 it wasn’t a death sentence, but public consciousness hadn’t got there yet. So, when you told someone they had HIV, they were still dealing with it as if it was a death sentence. Fortunately, what I got to tell people was that it’s not. However... yes. That... that’s the evolution.

But, prior to that, working... I mean, yes. I... I remember. I remember people coming into the hospital with their first, uh... I think, what’s the term? AIDS defining illness. So, first case of PCP, first diagnosis of Kaposi’s Sarcoma, and what their response was. I remember being asked, “Can you help me kill myself?”

I mean that... Coming from someone who was thirty, that’s... that was very... well, that just about says it all, as far as I’m concerned. Because people – people knew what the course of the illness was. You did not get better and you died slowly, and... by inches, often.

BK: Yes... Yeah, I don’t know – I don’t know how to respond to that.

PH: Nobody knew how to respond to that. I mean how... how can you respond? I remember... For posterity, I will tell you – I remember... I remember a fellow who had – he had Kaposi’s Sarcoma, but he had it internally. So, they had to do surgery to... because I think his bowel at perforated. So, they went in to resect his bowel. When they sewed him up, because of the Kaposi’s Sarcoma, the incision wouldn’t heal. So, for the rest of his life, which was spent at St. Paul’s hospital, he had an open wound that wouldn’t heal. So, every day we would go in and we would put a dressing – we had to put a dressing on his, on this bowel incision. And every time he coughed... the purulent discharge from the infection in his bowel flew into the air, and... He, uh... I don’t remember how long he lived, but I remember going in there and having to change his dressing. And there he was.

I remember a young fellow – he couldn’t have been more than twenty-four – and he had PCP, and he couldn’t breathe. And he was... That feeling of – of not being able to catch your breath... I mean, not just people with PCP have that. People with other respiratory problems have it. But he... there’s a rising sense of panic as you can’t catch your breath, and there was... there was no solution. He was lying, he was dying, and he was alone. And I remember sitting with him through the night so he wouldn’t be alone as he fought the panic of not being able to get enough oxygen.

And that’s what people’s lives were like. That’s what death was like. That’s what people who didn’t have HIV saw. That’s what people who just found out they had HIV knew was going to happen to them. And that there was no solution. There was nothing that anyone could do for you. [Pause] And that’s – I mean that’s what I remember. That’s what the – that’s what the AIDS epidemic was for me. It was watching that happen at work and it was watching that happen at – not at home, but amongst my friends.

And then, what you would see is, people would get sick – so you know... *You* know what it’s like to be gay, is that you leave home, right? And you move to a place where it’s ok to be gay.

Where you can be around other gay guys. So, we all did that. We all lived in Vancouver. Not everyone was from Vancouver – most people weren't. But then when they got sick, what happens? Well, you go home to your family. So, people who had... I remember... People who had left home because they didn't want to live there, their only choice was to go back to place that they didn't particularly want to to die, because the only people who would take care of you would be your family. Well, where else do you go? Now... Those – those would be stories that you should collect as well, you know... The family that gay guys went back to.

I can't tell that story. Those would be good stories to hear. But I know what it was like to be here. And, I mean, I always tell people that in 1984, I had a social group of – I don't know – forty or fifty guys. By 1989, I only knew three people. Now, not everyone died, or not everyone died here in Vancouver, but... everyone left... or died... or left and died. And that – I mean for me, that's part of what the HIV epidemic was, is that I lost my... I lost my social network.

And that coincided with the fact that now I was just... my life was just, um... I worked. Every day I worked and I worked in that environment. And then I came home and I didn't want to go out. I didn't want to make new friends. I wanted to hide. Now, that's a – depression, burnout – that was how I responded. Perhaps that's not the healthiest way of doing it, but I'm not here to give advice, I'm just here to tell you how – what happened to me.

BK: And that's why, when you said earlier that “what doesn't kill us, makes us stronger” doesn't actually really make any sense in this context.

PH: I think... I think that in the sense that it made the community stronger. I think in the long-run, I survived, and, in the long-run, I believe that I... I am a healthier, wiser person for having gone through that. But I wasn't at the time. I wasn't a healthier, wiser person in 1996, when the scope of this interview ends. I was... I was a wreck. And, I mean, that's part of the reason why I moved from working in acute care to working in prevention. And... Not because I felt that my – not that I felt that the work was more important, it was that I couldn't do the work anymore. I still feel, if I were a better person, I could have done it. But I'm not that person – or I wasn't. You know...

It's interesting – I think it's interesting. When you look... when, sitting inside, I look back... it's a, um, it's a time of great pain and failure. And that... They talk about survivors guilt. I'm not sure... I mean, it doesn't feel like guilt for surviving. It feels like guilt because I didn't do enough. So, I don't know. But... What I recall is not a sense of success, but a sense of profound failure. I suspect that it's partly because part of me wants to – I always want to solve problems and this a problem I never solved.

BK: I... Yeah... Talk about trauma.

PH: Uh... I was telling someone what I was doing today and... One of the things that doesn't happen very often is the recollection of these events. I think that's also a measure of trauma. You know, there's a lot of... there's a lot of sadness and, uh, and trauma attached to those days... But if you think about the parallel between an individual and the community, I don't know – I don't know... We certainly seem to have put it by... behind us very quickly. I mean, we talk about the

post- – I realize of course that calling it the “post-AIDS era” doesn’t mean that we’ve forgotten it, per se, but I think, well... You haven’t forgotten it. You weren’t around here to remember it. Is it part of – is it part of the collective memory? I don’t know. Because it’s part of my memory. I guess that would be – that would be something to ask someone else, whether – what does the community remember? Anyway...

BK: Is... Are there some ways in which you feel we could be – I think there must be but... Are there any ways you can think of that we can do a better job of remembering this as a community? Like, how can we do a better job of communicating – I don’t want to use the terminology of lessons learned but how can we relay these experiences in a way that is productive for our community, I guess?

PH: I don’t know. Think about our parents’ generation – well, your grandparents’ generation. You know, how do you... How do you keep the lessons of the Second World War alive? I mean, I mean it is our... It is all of our responsibility to remember the past. How can we remember, um, the AIDS epidemic? Obviously, this is something that you’re doing. It’s interesting... We don’t talk about the AIDS Quilt anymore, partly because they don’t – they don’t cart it around like they used to. They used to put – they used to bring it out and put it on display. I mean... I don’t know.

Could we do a better job? I think that one of the things – one of the things that happens is that we’re still dealing with HIV, but because we’re dealing with it in a different way, that – you know – we’re not at the point yet where we’re going to bring out HIV as something that is in the past. We’re dealing with HIV as something that is in the present and we’re dealing with it in that format, so... I think that that’s part of the thing that happens is that we’re still dealing with the HIV epidemic but it’s in the current iteration. So, really, as I often say, I really am just a dead hand of the past.

BK: Don’t you feel like there must be some relevance...? You know, people who are long-term survivors, people – like yourself – who have been caregivers since a very early point in the epidemic. I mean, there must be some relevance for current prevention efforts, or current treatment/support efforts.

PH: I think... Well, I think long-term survivors have a huge role to play in... in keeping that aspect... keeping what HIV meant and means, and can help people who are dealing with HIV in its current form. Dealing with the trauma and stigmatization. But, for caregivers, I don’t think we’re going to see HIV... I mean HIV as that disease is past. It’s possible, if there’s another epidemic of another disease that impacts a different community... Perhaps my experience will become relevant, but... You know, I remember... When epidemics happen, it seems we relearn these things all over again. I remember SARS. SARS didn’t have – obviously didn’t have the same impact, but it could have. And there’s also sorts of – there’s all sorts of epidemics that could have... You could look at the fentanyl crisis as being a – another type of impact and what’s happening in that community. And the burnout and the sense of loss and the overwhelming trauma.

But, what wisdom do I have to share? Nothing that people don't know already. Take care of yourself. If you're a caregiver, remember that you have to take care of yourself as well as others. But... it's all just platitudes. Putting it into practice... I mean, I always say that the work that has to be done is really an individual – it's really personal work. So, there's no public health campaign that could have helped me get through as caregiver. Therapy, perhaps...

BK: Yeah, I think the opioid crisis seems to have some interesting parallels, and I feel like there have to be lessons that can be applied. I mean, they're not the same thing at all, but... Just in terms of being a public health crisis that involves people who are marginalized and, basically, just how social this all is. There must be lessons from HIV.

PH: Right, and that's why they're marching in the Downtown Eastside. And that's why we should listen when they do.

BK: This is kind of a rephrasing of the previous question in a way, but do you have any advice for younger generations of gay men? Part of what we're wanting to do is to stimulate some type of cross-generational dialogue, because, you know... As a team, we feel like there's – and having talked to a lot of people in the community – we feel like there's not a lot of dialogue that goes on along – across generations I guess in terms of HIV and AIDS.

PH: Well... The question was: do I have any... is there anything I'd like to share?

BK: Yes, or do you have any advice, or...?

PH: Tell those young whippersnappers? Well, my mother used to say, "It's all fun and games until someone puts an eye out." I think that's how... I think that HIV has – the HIV, how we're dealing with HIV has changed, and I think that I have... There's not much that I have to say that's particularly relevant. I think that... I think that the lessons I've learned are hugely relevant to any individual because it's all about... It's all about learning how to love yourself and love others, which is what it's all about. But, I think everyone takes their own personal journey and I think that... I think that the issues around PrEP and how it's going to affect our lives are so different than what HIV – the impact of... of what HIV was like before the highly active antiretroviral therapy. I think that what I experienced... What I experienced wasn't about HIV. My experience was of what it's like when everyone you know dies. Now, god willing, that's not going to happen to young gay guys. They're not going to have to go through that, so... So, you know...

But, lessons learned around, you know, why it's important to be inclusive. Why it's important to practice compassion. Why's it's important to have a sense of community and sense of purpose. Why it's – you know, as they say, "if we don't hang together, we'll hang separately" – those are lessons that, I think that we all have to remember. I think one of the problems – one of the issues is that we... not only... It has been said that we're in the "post-gay era." Well... Maybe that's true. Maybe we don't need the community anymore. Maybe we are ready to integrate into society. Maybe there is no stigma. Maybe there is no need to be a community. But, I think we all need a sense of community. If you don't have a sense of community around being gay, then I hope you have a sense of community around being, um... a hockey player, or... a, I don't know,

Presbyterian... Because I think that, just being... not having a sense... not having a tribe is difficult.

We... less, now that we're allowed to marry, but we don't – we haven't had a sense of family. It's been our – it's been my experience that we have chosen families. Maybe that's going to change too. What I do know from what I do now for a living is that being alone and being isolated is a huge factor in gay men's lives. I suspect it's a huge factor in everyone's lives. But having a sense of community, having a sense of common purpose and a common goal, is a great – it's a great boon that it would be a shame to lose. Maybe we have to lose it, but... Maybe there is no "we." I don't know. I still... I mean, I still... One of the great advantages of being me is that whether the gay community – whether we're post-gay or not – I'm not "post-gay." I'm still "gay." And, whether you like it or not, I still think of you as part of my community.

BK: Any advice or lessons learned that you think could be applied to, like, current... So, no, you actually already said no to that... [laughs]

PH: NO! [laughs]

BK: PrEP. The era of PrEP, TasP... The "post-AIDS era." Like, are there things that healthcare providers can be doing better?

PH: Hm... Well, of course... We're moving into... we're moving into the era when everyone should be on PrEP – that's, I mean, I've heard that said: "Everyone should be on PrEP." And, you know, as part of what we do for – what I do, what I should be doing is getting everyone on PrEP. Is there anything else that I should be doing? Well... I still think part of my job hasn't changed, either as a healthcare provider in the community or a member of the community, or just as a human being, which is to give people a sense of safety. Give people a sense of community – at least offer them. And to allow people to know that it's okay to be whoever they are. So, if you want PrEP, it's okay; if you don't want PrEP, it's okay. If you're not sure you're gay, that's okay, too. And... and if you're afraid, that's okay. I think that... And if you don't want to talk about it, it's okay as well, and I think that... I think that being able to create a sense of safety and inclusion – which is part of what, for example, Health Initiative for Men, what their job is, to create that sense of safety and community. There's different ways of doing it, but, you know – there's the institutional way, but that's what we do as humans is... we create a sense of safety for our family, for our tribe. And... and try to extend that to the rest of society as well.

So, what was the question? Do I have any advice? Well, create that sense of safety for yourself and then start extending it outwards. It may sound easy but it really is a lifetime's work.

BK: Just going to take a look here. I think I've actually asked most of the things that I have on my list... I mean, I think we've touched on how your perspective on HIV and prevention has changed over time, I think... And –

PH: I think so. Surely, I've said everything.

BK: Yeah, I guess we... I guess we typically like to end then by asking if there's anything that you want to share that you haven't had a chance to share, or anything that you thought we'd ask that we haven't asked that you'd like to comment on...

PH: It's... You know, I think about the things... When I think about the past – when I think about what HIV means – I mean... Of course, a lot of my friends, now, have HIV. And then there's a lot of my friends who had HIV and they're dead. And... And the – the watershed, the idea that, that tremendous sense of loss and mourning that is attached to the past. And it is a marvel that now, you know, all my friends with HIV, it's not a big – it's not an issue. They take their pills and they're fine, and the medical community tells them that they will live as long as anyone else. And I think that that – I think that that's amazing. I hope that that remains the case.

BK: It is amazing.

PH: It is amazing. And I will just say this: because you are essentially interviewing people who have been around for a while that one of the things that I have found very interesting is that when this all happened – coming up to thirty... coming up to forty years ago; thirty-five, forty years ago. Now, of course, at this stage of my life – now of course, people are dying again, and how annoying is that? Because, of course, the thing that... the thing that we forget is that, it's true, the fact that so many people died when they were so young, the perspective that happens later on is, oh... “Oh, right. We're going to die.”

So, now the long-term surviv– the people who have survived – now we're dying anyway. And I always think that's a very interesting perspective. It's like, what the fuck? Pardon my language.

BK: It would give you a very – having gone through that would give you such an odd perspective on death and dying.

PH: Well, I think that it's not... Well, it is odd, but, you know, I think about my father's generation. My father fought in the Second World War. A lot of his friends died. And I think that what happens is you deal with that in a certain way. For example, with HIV, you could do things that would decrease your likelihood of catching HIV and dying, but, of course, you can do things that might postpone your – at this stage, you can postpone it – but of course, death happens to us all. And I think that – that's the difference between the... Well, what we all learn at the end of our lives, which is that compassion – the compassion that the HIV crisis taught me when I was thirty, now it's the compassion that you learn at the end of your life when you realize that we really are... it isn't all... it isn't all forever. It is... it is a precious gift that we have. So, I think that... I think that what we have – what we now experience as elders is a second attempt, or a second lesson in compassion and care for those around us and ourselves.

BK: And that first lesson, has in some ways prepared you, in some ways, for this?

PH: I think so. I think it's still a shock. I think it's always a shock, just like it's always a shock... it's always a shock when you tell someone they're HIV positive. It's always a shock, the mortality. However, as I remember... I remember so often one of the things that people who had HIV have said is, is that, “Finding out that I had HIV taught me how to live.” And I think that

facing mortality, one way or another, is a – is one of the... it's one of the stages that we all have to go through. And whether you do it when you're thirty or you do it when you're sixty, it's still something. It is just part of life. It's not the nicest part of life. But, regardless...

BK: I think that's part of the impetus for why we want to do this project now, is because we do realize that there's not a lot of people, anyways, from this generation, especially long-term survivors, so... And now they're aging, and yeah... there's way too few of them.

PH: Yes.

BK: So, it's important to collect these stories now... Any final... any final...?

PH: I think I'm done.

BK: Okay. Thank you so much. I'm just going to stop this.

[End, 1:49:52]