

Charles Irvine

[00:00:00]

PARTICIPANT: Um, my name's Charles Irvine[?] [00:00:03], I'm originally from Glasgow, I moved the Manchester approximately thirty-ish years ago. Prior to that in Glasgow I— I'd basically done bar work, hotel work, that sort of thing. But even prior to that I'd been in the armed forces. However in relation to, if you like, this, I first became aware of HIV in the late 70s, but it was not known as HIV at that particular time. It was known as GRIDs and there was a small booklet that I found in the Glasgow library. It explained, if you like, that there was this plague that was affecting the gay community in San Francisco. The peculiarity of it was, that, it was be— it was highlighting a cancer called Kaposi Sarcoma which is very common in Mediterranean— the Mediterranean population. However it was hitting the gay community in San Francisco. They eventually managed to come— sorry, they eventually managed to get... No, you'll have to stop the sentence there.

[00:01:36]

INTERVIEWER: That's ok.

[00:01:48] [Break]

PARTICIPANT: They eventually managed to find a test called uh— I'll give you two, and I can't remember which comes first. And there's a Western blot test, and then there was the ELISA test, whichever came first, we threw out numerous false positives, and false negatives.

[00:02:15]

INTERVIEWER: Yeah.

PARTICIPANT: They then— the second test that they'd done, eventually, eventually when they found it, um... kind of balanced the negatives and the positives, so there was more chance if you were told you were positive that you were definitely positive. However that, over the years, still didn't help a great deal. I actually know of one person who is no longer with us, but lived for, five, six years? And they were living at the time with an HIV diagnosis, and they'd been accessing services from HIV groups. However, after something like six years, they were found to be negative. That's not the say this— it was the person that was at fault there, it was actually the testing at the time.

Myself, I was diagnosed mid- to late 80s, and I was diagnosed in Glasgow. And, that was... it was an unusual way to be diagnosed because I was taking part in a drug trial in Edinburgh, part of— part of the criteria was that they were doing HIV tests, and my HIV test came back as a positive. However when I was diagnosed, then again it still wasn't HIV, I was diagnosed with HTLV-III. It was only some years later that they changed it to HIV. And then HIV and AIDS, although the majority of people at the time, it was just AIDS. And the— hadn't been diagnosed. There'd been very few, if any, services in Glasgow. I'd always been very open about my status, even in

the early years, to the point where I'd go into my local gay bar and it was like Moses parting the Red Sea. And people would actually say to the bar staff, "We don't want the glass that he's just drunk of— drunk out of", um, which was a bit, kind of, off putting.

But. Then again, the positive thing there was, that the lady who managed the bar would contact me if somebody had been newly diagnosed, because at the time, then, it was— you got a diagnosis, and basically it was a death sentence. Most people would be dead within 12 months. And, there was no treatment whatsoever at the time, and— that only came later, with the advent of AZT, and, but even with AZT the— the strength of the dosage, they were still trying to find what would work. But it was that toxic— it was AZT that killed people. However they did come to finding a dosage that was workable. And, and that was done through the Concorde trials. The Concorde trials was the first HIV trial ever done in the UK, and about the only thing that we learned from it was how not to run a drug trial. But, that again, has got a positive note to it, because nothing was ever done the same again. Um...

[00:06:18]

INTERVIEWER: What was— what were the problems with that trial?

PARTICIPANT: They, they— some of the major problems were there... It was supposed to be a double-blind trial, but doctors were chopping and changing it, because they would see some progression with the use of AZT, and it did, it helped some people, but predominantly, because the dosage was that high, it didn't. And I think— I also think, I think it depended on the length of time that the person had been diagnosed. Well, I say diagnosed, but the length of time that the person actually had lived with the virus. And, that would be— they wouldn't have known that they had the virus at the time.

[00:07:11]

INTERVIEWER: Yeah, so at what point they got diagnosed, they wouldn't have—

PARTICIPANT: Yeah. I think it was the later... the later that you were diagnosed... Sorry. The earlier you were diagnosed, AZT was beneficial. If you'd had the virus for a number of years prior to that, then that was, wasn't because the toxic dose of AZT that they had to give people potentially was killing them. The body was rejecting it at tremendous rates. I won't go into some of the sights that I've seen, but um, some of the Egyptian mummies in the Victoria & Albert museum actually look better than some of the people that were still living with it, and in the late stages of AIDS. Uh...

[00:08:08] [Break]

You're gonna have to stop the sentence.

[00:08:08]

INTERVIEWER: That's fine, don't worry. Do you want me to stop recording?

PARTICIPANT: Yeah if you could do just a second? And try to get me back to—

[00:08:19] [Break] [Recording stops and resumes]

INTERVIEWER: OK.

PARTICIPANT: The Concorde trials showed how not to run a trial, and so it did have its pluses. We then started to find various different drugs that seemed to have the potential of being beneficial. One of the major things that everybody was on about was a vaccine. And, then a cure. But the vaccine would be the first thing. And, trying to explain to people, when you're talking to people, that if they were HIV positive then they— to get on with their lives and live it and thoroughly enjoy themselves, because the chance of a cure in their lifetime was negative. And, so, I would never give anybody false hope. Having said I wouldn't give them false hope, I wouldn't— I also wouldn't shoot them down in flames. It was a kind of sticky situation of making choices at the time. Um, in Glasgow as I say, there was very few, if any, services, at all. There was one group which met once a week, and it met at Ruchill Hospital. The group consisted of, I think seven or eight people at the time, and it was very hush hush. You had to be recommended by your consultant, you went to your social worker, then, put it to the group, and if it was acceptable, you were then invited along. The day that the group met changed constantly, because even though it was within the hospital facility, the stigma that was attached was unbelievable, totally unbelievable. That— that never ever sat well with me, and there was a group in Manchester that were holding a [missed] [00:10:56] weekend at Hebden Bridge and some of the group in Glasgow were invited, so I went along to that, and I saw a whole new viewpoint on living with HIV because the majority of people that I met from Manchester, they were being empowered to live, and not being, taught to die if you like.

Having spent the weekend at Hebden Bridge, we then headed back up the Glasgow, which was fine, but a friend in Glasgow who was not positive at all, was moving down to Manchester. And I came down a couple of weekends, stopped here, thoroughly enjoyed it, and decided to move down. There was no problem, I got accommodation down here, I spoke to my consultant in Glasgow and told him I was moving to Manchester and could everything be dealt with down here? It was no problem and he sent me to the Hope Hospital in Salford. Which, very quickly, and not from myself but from a number of people, got their— got the name of being the No Hope Hospital. Their idea of— oh, the... The person from social services that dealt with HIV at the Hope Hospital had this hand touchy feely thing, and if there was something the matter, it was, "Come on, I'll give you a hug", and that something the matter could be anything from they'd just been thrown out of their house because they were found to be positive and they were in private rented accommodation, or they'd just been thrown out of the family home, or, the whole family turned their back on them, and this person's attitude was, "Oh come on, I'll give you a cuddle". Well at that time, as somebody said, "I don't want a fucking cuddle, I want a house". So, I'm not saying that that was bad, at the time, people didn't know, and even today, still don't know, what somebody with a diagnosis of HIV actually requires unless they listen to that person themselves because each person is individual.

But... I've quickly found that the Hope Hospital wasn't for me, and I quickly swapped to North Manchester General. My apologies, I didn't— I swapped to the Monsall Hospital, because there had been a specific unit built there to treat HIV. And part of the reason for that was, prior to my moving down, a person who had become a friend after I'd moved down, had been taken into North Manchester Hospital and he was the first inpatient in Manchester, and they found it very difficult for nurses, doctors, basically the general hospital staff... There seemed to be a difficulty in them dealing with the person, to the point that the food used to come on paper plates with plastic cutlery; and some cases, it was left outside the room, and they were in the infectious diseases ward, but it was... I'd say completely cut out, almost like a bubble. So, they gowned up and everything before they went to see people. Then, some of the nursing staff thought, "Well this is bloody stupid", and they then volunteered to work within that unit.

The Monsall Unit then came to fruition from that sort of thing, and there was monies found to build the unit, and it was excellent. At one point I would say, it was— had a far better reputation than any of the Lighthouse etcetera down in London. And, with a lot smaller budget than the Lighthouse and that in London. But they progressed and eventually, the stigma, to a degree, within the hospital situation, became lower. And part of that, I think, was because of people who were positive at the time were turning round, and they were brought into the equation. It was, "Well, if we're going to treat you, how do you want treated?" And people did turn round and say, "Well, there is— we already know how we're treated, and there is already standards set in stone within the hospital, and that's universal precaution, so when you take blood from anybody you glove up, you don't— if there's a blood spillage there's ways of cleaning it up, those standards have always been within the hospital". So, to go in to have your bloods done and see somebody that is having blood taken by a nurse, and the nurse doesn't have any gloves on or whatever, and then when you walk in, they automatically gloved up, that was a little bit of a [missed] [00:17:17].

Dental practice, that was even worse. But. The hospital at Monsall eventually... I'm not sure if it was through the council or whatever, but amalgamated and with North Manchester and the Monsall unit was created. At that time, it was probably about the time that I became involved with BP [Body Positive], because— or slightly before that, because there was fundraising that needed to be done. And that was for— to make it more comfortable for people that did go into the unit, because invariably if they went in, that was it, they rarely came out alive again. Although, as it progressed, it got better. People would go in and they would be treated, and come out. But they were treated, if you like, in a holistic way, whereby the whole person was treated, not just the disease. So if somebody who was HIV positive then found that they developed, as I did at one point, a throat cancer, automatically it was all done within the unit. That now, because of various budget cuts etcetera, doesn't happen. What happens now is, if you've got a problem, you go to your GP. If it's an HIV problem, you go to the HIV unit. However, they— we do get the point whereby, you go to the HIV unit and you turn around and say, "It's nothing to do with HIV, you have to go and see your doctor". Your doctor turns around and says, "It's nothing to do with general practice, you'll have to go back", and you get passed back from pillar to post. That is the reality, today. Twenty-five, 30 years ago, the reality was, you were treated as a whole person, and your treatment was run between you, your consultant, and if

you had one, your GP. So it went round in a circle. Now, it— you can go in a bloody triangle.

[00:19:49]

INTERVIEWER: Yeah.

PARTICIPANT: I've been told that there was a legal case brought up that ended it and did go to court, and he got released. So basically he was going to prison for having an illness. Admittedly I don't think, and actually I don't believe that illness was the main issue, it was the fear that people had in relation to that illness, and the fear had been generated, if you like, at the end of the day by the media. And it was playing on people's bias, because at the time, the only people that were coming forward and being diagnosed with HIV were either gay men or IV drug users. And, that was perfect as far as the media was concerned, because they were trying to enter a media frenzy, as they did do. Which, I believe, well in my own opinion, ultimately, has caused the stigma to continue, and still continue to today. Because it's easy enough to teach somebody something; try to unteach them, it's another matter. And that is the problem we've got nowadays, is actually trying to unteach people what they perceive as facts that we taught them 30 years ago. So you've got a whole generation coming up with that.

[00:21:28]

INTERVIEWER: Do you remember the "Don't die of ignorance" campaign? It's the first major government response—

PARTICIPANT: The— the iceberg.

[00:21:39]

INTERVIEWER: Yeah.

PARTICIPANT: It's not what's on the top, it's what's on the bottom. Yes. I do remember that, because the other thing that came through in that was that it was preferable to find out somebody's status before you had sex with them, and, even though the condoms provided, and you could get condoms— because that was another issue, but— you could use condoms and, at the time it was the only protection that was known about. However there was still a stigma attached to the condoms, there was the religious bit and all the rest of it. There was, the twin set pearl brigades, saying, "Well why should we be providing, financially providing free condoms to gay men when the money could be used toward the maternity unit or whatever?" So there's always been that sort of stigma. I believe that that initial, the iceberg moment, there was something should have been done at the time, that was done at the time, but I think it was the wrong thing that was done at the time, because again it just reinforced a lot of the stigmas that were attached to HIV.

At the time it was Terrence Higgins Trust and a lot that was very beneficial. However being a London-centric based organisation, everything seemed to be in the South, in or around London. There was very little outside. So any organisations that did come

to fruition outside of London found it difficult to get funding. The majority of the funding would come from NHS budgets, social services budgets, and, with those there's always been huge pressures for where the money goes. And this was something that was brand new, so it had to be extra money if you like. The government did provide a certain amount of extra money, but a lot of that, I believe, was misspent. You had different organisations at the time that, if a member of that organisation was going to, say, Paris for an HIV summit, they only would travel first-class, they stayed in the best hotels. So it was money— of the amount of money that was spent for somebody to attend a conference, for argument's sake, with some of the organisation's administration, only some, a lot of it was misspent.

[00:24:51]

I, at one point, went to the World AIDS Conference in Japan, but I actually saved up for two years to do that, and I got, from Manchester health service, they paid me £300 toward that, and it cost me nearly 3000. But that was my choice to do, because I found— that was not the only conference I'd attended, I'd attended a number of the World AIDS Conferences, which were held every two years. I found them interesting, and also, you were able to input globally, and it was, they encouraged people with HIV to attend these conferences, so it wasn't all medical, there'd be psycho-social and all the rest of it going on. But people could then network. The voluntary organisations were in a position where they could network together, and share their experiences, and out of that a lot of the ideals and the ideas of self-help groups came, and what could be offered in relation to different therapies, and holistic therapies, various things. So it was not all mainstream medical facts and fiction and all the rest of it. But the medical facts are, ultimately that there was a lot of infighting within the medical profession, because you had two major professors arguing who had discovered the virus first. I know Montagnier was one, but I can't remember the name of the other. So it was... it was almost— well, I say it almost, it did— HIV, that tiny little virus created a multi-billion-pound industry, globally. And still does to these days. Which is a great pity, because a lot of the money could and should be spent better. I always try to look at the fact, or, purport the fact to people that HIV is an illness like any other, and should be dealt with as an illness like any other.

However I honestly believe that the— when they changed the way that they funded— or when government etcetera changed the way they funded HIV, which is used to be ring-fenced and could only be spent on HIV. Then it ended up, they changed it and it went into mainstream funding, and since this went into the mainstream funding, there has been a rise in HIV within probably the younger gay population, but also within the heterosexual population. The reason for the heterosexual bit is because of the information that they were originally given, that it wasn't a problem for them, it was only poofs and junkies who got HIV. A lot of the heterosexual population representing late- and, with HIV, so, it was going onto an AIDS diagnosis, so they're kind of finding out in the later stages of their illness, because again, because of the way that it had originally been tackled, doctors wouldn't think, a lot of doctors wouldn't think to say to a heterosexual person, "Well, have you considered an HIV test?" They would test for everything else, come up zilch, and rarely would they say— well, because they had been given, a lot had been given the same information. Or their source of information was the media. And the

way the media had dealt with it— and it created a certain— sorry. To a certain degree it created closed minds, that they could only picture gay men and IV drug users, those are the only two people.

[00:29:43]

INTERVIEWER: Yeah.

PARTICIPANT: When you turn round and say that, something like 40% of Sub-Saharan Africans were HIV positive, nope, that didn't come into the equation, because that wasn't part of the country.

I remember once doing some fundraising for the Village charity at the, what was then the Hacienda. And, when we arrived, it was a reggae night, so it was full of Afro-Caribbean. But, fun night, but when we approached somebody to see if, "Would they wear a red ribbon, and if so, would they like to make a donation for it?" They didn't have to, because the red ribbon was never supposed to be to raise money, it was to raise awareness, it's now become a money-making scheme. However, you'd have these large... Afro-Caribbeans turning round saying, "Well it's nothing to do with us. It's all the poofs and junkies". A number of the people there raising money at the same time as I was, kind of backed off and took a back seat. Myself however, because of the knowledge that I had, I was able to turn around and say, "Well I appreciate exactly what you're saying, however, in Sub-Saharan Africa and part of India, and parts of South America, the— HIV is the number one killer." When I started to get to facts, you could see that it gave them pause for thought. Now whether they then went away and found about more[?] [00:31:45] or whatever, I have no idea. But organisations like BHAF [Black HIV/AIDS Forum] started to appear, and they specifically dealt with, if you like, Black Afro-Caribbeans, and Asians, Chinese, but they couldn't— it was good, it was extremely good that that was being dealt with, but because it was being dealt with by an organisation— a specific organisation, specific to that group of people, it then pulled away from the other organisations. Instead of HIV bringing us together, it was kind of... No, sorry. The HIV was bringing us together, but the attitudes of some people were drawing us apart.

[00:32:45]

INTERVIEWER: Ok. Could you say a little bit about how it was for you, if you're comfortable, talking about how it was for you personally, with this diagnosis, how you navigated your sex life, and how you interacted with people, and you know, it might not have been different, but what kinds of attitudes you encountered in terms of—

PARTICIPANT: Um, when I was first diagnosed, I fell into a bottle of gin, actually, a couple of crates of gin. And for about three or four months, I then gave myself a mental kick up the backside, told myself, "Right, you've got to get on with it". Still knowing, the information that I had at that time, that I could get an infection at any time, and that would be it. So you basically lived day to day. At the time I wasn't— I'd stopped working, and I had to go to the job centre, or the [missed] [00:33:55] as it was called at the time, but, went to the job centre for an interview, and the minute I brought up the HIV thing, I was basically told, "No, don't worry, you don't have to

come back and see us", and that has continued literally up until the past three years. And, the major reason for that was, the job that I had done, because of the industry that I was in which was the catering industry, the— there was chances of you cutting yourself, this that and the next things. Again there was major assumptions made. And, there were certain groups of people that were put in the position whereby it wasn't that they were unemployed, it was that nobody— to a degree, that nobody would give them a chance. And because of the HIV, they actually became— and statistically, became unemployable. That was almost a government viewpoint, that they were unemployable. I mean, that's been changed now, but that's come in leaps and bounds with the medications that are available, etcetera. However you've still got a small percentage of people, that are still alive after 30 years and more, that were basically told, "You're of no use whatsoever to society". And you've now got this government turning round and saying, "Well, you will be of use to the society" but that's hard to get your head around after like 30 or 40 years.

And one of the major things that's, in relation to HIV people don't understand, especially for people who are long-term survivors, is you actually, almost on a daily basis, you live with this guilt that you have survived, and all the rest have gone. And you do, even now you can see your friends, friends of a number of years disappearing. That's ok when you get to my sort of age, because that's acceptable when you're like, 60, or nearly 60. But when it was happening way back when, and there's like, 20 years olds losing half their... half of their friends, and people of 30 have lost two thirds of theirs. You get people in their 40s, there's none of their friends alive. That is difficult, that is difficult.

And even though the— at the moment, there's a lot of things coming up with Truvada and things like that, there's still that, I honestly believe people still have to kind of think before they act. Because it— a lot of the younger gay community believe that Truvada is the magic bullet. Well, it may be the magic bullet at the moment, however, if... It's not the magic bullet for everything. So they think that if they're on Truvada, then that's fine, they won't catch HIV, but they might catch something else. There's also the bit, if you like, in the relation to the older gay community, that it's their problem. So you do get a lot of the younger gay community turn round and say, "It's nothing to do with us, it's your problem". And, going back to the iceberg bit, the one thing that was always said, or we always tried to put out—

[phone rings] Was that me? Oh, it's me. Sorry.

[00:38:39]

INTERVIEWER: No, that's ok. I should have asked you—

PARTICIPANT: I completely forgot. Excuse me a second.

[00:38:46]

INTERVIEWER: It's alright, don't worry.

PARTICIPANT: Hi Antony. I'm fine.

[00:38:51] RECORDING STOPS AND RESUMES

INTERVIEWER: Ok.

PARTICIPANT: Going back to the iceberg bit, one of the things, in those early days we tried to get over was, it's not who you sleep with, it's who they've slept with. So, you may think to yourself, "That's my first time, I can go in, I'm having sex with somebody, fabulous", and as a youngster you go, "Oh, it's fab!" because it's unexplored territory. However the partner that you would choose at that time, you don't know what their sex life had been in the past. They could have slept with ten, 20, in some cases hundreds. And because of the way the virus acts, and turns itself into that person's genetic code, it then can be passed on. But any one of those thousands— sorry, and one of those ten, or 20, or 30, so you should always turn around and say, "You're not just sleeping with one person, you're sleeping with that one person and all of their sexual partners, or previous sexual partners". It was a bit difficult for people to understand that, but some people actually, and did, take it on board, and can reduce their sex practices or were... Or they practiced safer sex.

In relation to myself, as I said, I've always been fairly open about— or very open about my status, but that's purely for my benefit, because I could never forgive myself if I realised that I passed, potentially a life-threatening illness onto somebody else. So, my sex life became virtually zilch. And, not the easiest thing to do when you're like, at the age I was when I was diagnosed. I did have sexual partners, but I had to know that those sexual partners were themselves positive. And it was almost like then an excuse. I couldn't then say, "Well", if that person died, I couldn't then say, "It was my fault". So my sex life has not been that great. But, it was a choice that I made. I wasn't forced into that choice. And I know that there are organisations even now that will try and force people into that choice, of saying, "Sex, you're abstaining totally from sex". Well, as far as I'm concerned, that's wrong. It— with hindsight it was wrong for me, but, I believe it's wrong for anybody to turn around and impose their thoughts or their beliefs onto somebody else.

So, as far as the sex life's concerned, for myself, not a great deal, really [laughs] not a great deal. And, but as I say, it was a choice that I made, and it's a choice that I stand by.

[00:42:29]

INTERVIEWER: Mhm. Ok. You talked a little bit earlier about the kind of responses you got from within the gay community, I think you said something like you walked into that bar and it was like Moses parting the waves—

PARTICIPANT: Yeah.

[00:42:45]

INTERVIEWER: —and, could you say a little bit more about that?

PARTICIPANT: I'd... now, this was in Glasgow. I've had people that, the bar staff were actually told to, like, discard the glass that I drank from. Now that, I'm not

saying, is the bar staff's fault, and I'm not saying that it's the manager's fault. It was, they were complying with what the majority of their customers wanted. And, I honestly don't believe that I can turn around and say, "They were wrong" because at the time, with the information that they had, they were right. Because, they didn't know— it wasn't known if it could be passed on by contact. But that, the thing with glasses was, they were always on about bodily fluids, so automatically, it would be, "Oh, it's a glass they've had, how long has it actually stayed there? And, even if it's been washed, is it still alright?" So there was all these questions going through people's minds. All I was able to do was, basically be myself, and try to, if you like, to a degree, educate people. I'll say to them, "Well look, no, there's no problem". Because if there was, if you were giving somebody a blow job, and... if somebody was giving you a blowjob, and they were HIV positive, there was—" and it was known at the time— there was something in saliva that suppressed the HIV virus. But that wasn't known by the wider public, it was known within medical circles, and those in the know if you like. Um, it didn't kill it completely, but it did suppress it.

Common sense, to me, common sense tells me that there was a suppression, there still is a suppression in saliva, and if a person did, feel free and cum in your mouth, and you swallowed it, then the acid in your stomach is enough to kill it. However there's the bit between the mouth and the stomach, any cuts or whatever. That, one of the major things was, always turn around and say to people, "Good oral health", and "Whatever you do, don't like, fanatically brush your teeth afterwards, because if you cause your gums to bleed, then you're only allowing a passage in". Other things like, if you cut yourself, people would go, "Ooh!" Well, you go, "Well don't worry about it, because—" or, if somebody else cut themselves, and you went to help them they'd go, "Oh no". Common sense, the blood that's coming out of that person is being out— whilst that's being pumped out, it looks— it could be a small amount of a large amount, whilst that's being pumped out, nothing can go in. But these were not things that were taught to people, it was just the, major, "Ooh, be careful". At one point people thought if you walked into the room with somebody that was HIV positive, and you inhaled the same air that they ever breathed in, that was it. [snaps] And we have come a long way. Still got a long way to go, but we have come a long way, because there is still stigma, and in the gay community today there is still stigma.

[00:46:40]

INTERVIEWER: What do you think— it sounds like a... But what do you think, the impact of that stigma is on people's sense of themselves, people, I mean, maybe—

PARTICIPANT: For— I used to go on behalf of BP and talk to various groups.

[00:47:04]

INTERVIEWER: Could you say a little bit about Body Positive and what your involvement was in the organisation?

PARTICIPANT: Right, well yeah. Historically, Body Positive started, Body Positive North West started but with six people in a small office that they managed to rent. I think they got some funding from the health service, or social services, one of the

two. And they started a small group in Newton Street, and they were there for some months. Then the landlord found out what the group actually was, and evicted them. They, at the time, their main contact was the George House Trust which was basically a self-help phone line at the time, this was right back at the— and they came together. These two different organisations were kind of... partnering each other if you like. Because the George House Trust was a service organisation. It was there, and is still there today, offering services to people that are HIV positive. Whereas BP was, I said, in itself purely to empower people to live with the condition. And services organisations kind of disempower people. In various stages...

Well— they then, kind of married up together, they managed to get funding, and they built... They built a purpose-built building on Shudehill Road. It was then that I moved down to Glasgow— from Glasgow to here, and I went there for the first time and visited for the first time. Got involved doing the helpline, and became the minute-taker at the BP meetings, and after about a year, there was the election to the board, and I was encouraged to go forward for that which I did do, and I was on the board for seven or eight years. And during the course of that seven or eight years, BP and George House Trust had their differences and parted, and BP got accommodation on Tariff Street. And offered the services that they had at the time, and from those premises for about five years or so?

[00:50:42]

They then got premises in Hulme, which I can't really go into because at that time I'd left. I do know that the premises ran from Hulme for quite a while, it was an old primary school they got. And it was purchased— I believe it was purchased from Manchester City Council, or the education authority, whatever. Then, some years ago, I think about six years ago, seven years ago, BP then basically dissolved. I think that's the nicest way I can put it.

[00:51:28]

INTERVIEWER: And when you say... could you tell us a little bit about what you did within the organisation and say a little bit more when you say it was focused on empowerment, and what you see the difference being?

PARTICIPANT: I think in any situation, you will always find, if people are given an incentive, they'll strive for that. But you will always have a small group of people that, no they won't, and they will always see themselves as a victim, or they will see that life's against them and they feel this entitlement. The ethos of BP was it was there as a net. If you needed that net, then it was there to catch you. And to help you, your next step along the line. There was always some people that slipped through that net, and there was always some people that were under that net. In fact there was one trustee that used to call certain members "dead links" which I thought was absolutely appalling, because the fact that BP existed, it was there for anybody who walked through the door, regardless of race, creed, colour, sexuality, the whole, right across the board. We were there to help them. Now I personally, through helping them I actually helped myself a lot because I got a lot from the giving.

It was done in a voluntary capacity, I was never paid for it, although I got my out of pocket expenses, but what I got from it was the empowerment. I felt that I got more from helping those people— "helping those people"— from helping people than I was actually giving. So again, for me that was empowerment, because it gave me a reason to get up in the morning and go out, and I would go down to the office, and I'd be there for the whole day. So it was basically like a full time job without getting paid. Although, having said that, don't get me wrong I was on government benefits. But if the same job had to be paid for, at that time, I would have been getting, at that time, something like 27 grand a year. You're talking about 20 years ago. So that's— that would have been a fair whack, I hate to think what it would be now. But we, Body Positive, because it was self-help, and empowering people, virtually everybody that was there initially... initially everybody that was there within BP, none of us got paid. However we did realise that for continuity there would have to be at least one person paid— a paid member of staff running the office and that sort of thing. And that's when we employed the first person. And then we employed a second person half time, because we used to offer subsidised lunches, so we knew that— and the person that we got half time was a cook. We got separate funding for both of those. So, the funding that we got came again for the group itself was spent on the group. Everything— we would ring-fence everything, and eventually if one heading was overspending, we would either cut back on that, or we would look for other funding for that, or we'd try and look at a way of, not shifting funding but kind of... this sounds bad, but moving money from one head to another, and so that the services could still be offered. And we did, at some point, at least once, we came a cropper where couldn't justify having this particular thing, and there was no money coming in for it, whatever, and we had to get rid of it. That was the short of it, we just had to get rid of it.

[00:56:46]

INTERVIEWER: So, you mentioned subsidised lunches. What kinds of other activities, services, things like that—

PARTICIPANT: We had therapies being offered at BP, we had aromatherapy, massage therapy. I think those were the basic ones. The major thing of BP was to encourage people to come out and get involved, and they could come in— because it was open five days a week, they could come in any time during office hours, basically.

[00:57:24]

INTERVIEWER: So it's like a kind of social centre, community—

PARTICIPANT: So it was like a social centre, it encouraged people to come out instead of, like sitting in the house waiting to die, basically. But give them encouragement to come out. It was predominantly gay men that came. We did have some families, but, yet again, there was a stigma in relation to IV drug users, because that was where the families were basically being drawn from. And there was a stigma between gay men and IV drug users, and vice-a versa. And I don't think that would— well at the time that I was there, it was virtually impossible to work out how we could get a... a balance. And, there'd been— there was a couple of times

when things would go missing from the centre, and it wouldn't be small things, it would be like televisions, video recorders, computers. And at the time, the only people that were there were the IV drug users. And to try to install into somebody whose secondary problem, because— I don't know how it is now, but back then, it was, as far as IV drug users were concerned, HIV wasn't a problem. That was something that might or might not happen. They lived on a day to day basis for their drug of choice, whichever that might be. So, to try and explain to somebody that they're not just stealing from the organisation, they're stealing from everybody that's using that's using that organisation, and everybody's in the same position as them. That was... I'm gonna say it, they didn't quite understand, but that's wrong. I know that's wrong. But. It was just, if you like they had different viewpoints, of what is and what isn't— in fact, there was once where, I think we were moving from George House to Tariff Street and, we'd got some funding for Tower Street for the rent for a five year period, and I remember one of the IV drug using members, turned around and said, "Well, can't you just like, split it all up and give each of us, whatever, and everybody gets theirs and then they can just go and—" like the concept of coming together, and working together, just wasn't there.

[01:00:48]

INTERVIEWER: Right. Ok. We're over time. If you want— is there anything else you'd like to say, anything we haven't covered, or any memories that stand out for you in terms of maybe how things have changed, or what it's like today?

PARTICIPANT: I think that it's a lot easier for people today. However, somebody in my position can see the difference, in standards of the services that are offered. More so within the NHS. I'm not saying that they're not good, I think they're extremely good, however, compared to what they were to begin with, I think they've gone on a slippery slope down. Part of the reason for that does come down to funding, and it comes down to the attitude of those people who are designating where that funding is going. And HIV and sexual health isn't the majority of people's first priority. So it's like, the kind of poor cousin of the NHS.

[01:02:31]

INTERVIEWER: Ok. Ok. That's sad. Is there anything else you want to add that we haven't covered?

PARTICIPANT: No, but what I would like to say is, in relation to HIV, as with anything else, yes it's wonderful, it's great to keep an eye on what's ahead, but don't forget what came from behind, because without what came from behind, we wouldn't actually be here today. And that I think is lost on a lot of people.

[01:03:05] End of transcript.