

## Martin Wells

[00:00:00]

**PARTICIPANT:** I'm 63, I was born in 1954. I came out when I was 27, which was like, very late 70s, early 80s, and yippee, I was gonna enjoy myself. But guess what started in the early 80s, from America. And, ultimately, my first boyfriend actually died of AIDS in 1990. He'd caught HIV but then there was AZT and effectively it didn't do anything for him, and he died. So not only that, in my early 30s— obviously that was very traumatic, and in my early 30s, I was starting to buy me own property. Don't tell your GP you're gay, because you won't get a mortgage, because gay people get HIV, gay people die, gay people are not worth life insuring, therefore you can't get a mortgage if you don't have life insurance. So... kind of pretty traumatic, which would lead me on to one or two other things actually. And then obviously Margaret Thatcher. Clause 28 is it? I can't remember. Yeah, Clause 28.

So, I'm of the age where people get prostate cancer. I'm of the generation where you don't talk about being gay because of HIV way back in the 80s. So to get guys who get diagnosed with prostate cancer, there's a link, not medically with HIV, but there's definitely a link with the psychological impact HIV has had on anyone talking openly about their sexuality. So. Pretty traumatic. Actually I didn't realise, I can now connect with that, I've not connected with that question recently, and I could feel a connection going inside me, because seeing my boyfriend having to deal with the question, "You need to have chemotherapy, and if you don't you will be dead within three to five weeks, but by the way, the side effects are so bad you will probably want to die", and I'm thinking, "Wow, now that's making a decision. Getting stuck in traffic, this that and the other, that is not a problem." So it's amazing how I've learnt so many things by being around very close people who've had to deal with HIV/AIDS.

[00:03:00]

**INTERVIEWER:** Yeah. And where were you at that time, what did you notice about the community that you were in and the atmosphere sort of around you? Can you talk about that a little bit?

**PARTICIPANT:** When I look back at where I was at, if that's a way of putting a stake in the ground, I was having a good time. And this— looking back again, I was brought up in a household where we did not talk about sex. Sex was definitely a no no. But because it was such a widespread no no, I didn't know any different. It wasn't like, "Oh, my mum and dad don't talk about sex", I just didn't even know, we didn't talk about it. And I was pretty screwed up, I now realise when I look back, about sex. That saved my life.

I remember when I came out, and I'd go out on the scene, I definitely wanted to get screwed. But I was so scared of somebody getting shit on their dick, I never allowed it to happen, purely because of that. That probably saved my life. I'm sure it saved my life. I would have been HIV positive, I probably would be dead, just like my ex-boyfriend— like the boyfriend, my ex-partner.

So, strangely, strangely, I don't know whether it was something inside me, but it kind of made me want to be more adventurous, having my boyfriend around, who's HIV—we'd split up at that time. So I was on the— out on the scene. And I remember a real dear friend of mine, she said, "Ooh, I hope you were safe last night Martin", I was like, "No, I wasn't". And eventually after a few times of asking me that, she looked at me and said, "I'm not gonna ask you any more Martin. And I will visit you in hospital, you know." [Gulp noise] Suddenly I got it.

Another thing, you I presume are in your early 20s? Uh, a lot of people don't— can't understand this, the only place you could buy condoms, it was either a male barbers, we didn't call them hairdressers, a barber, or Boots the chemist. And then it was really really embarrassing. You know that expression, "Something for the weekend, sir?" That's where, "Would you like a condom? Have a little bit of sex?" That was the only place, and you did not talk about it. So when you can buy them in, you know, put 'em in the slot machine in the toilets, you can buy 'em in record shops, sweets shops, you name it— such a difference.

Final thing I'd mention is the, looking back at the AIDS advert, "Don't die of ignorance". Such a controversial advert. There was no sanitary towel adverts on the television, and eventually when they did come out, you know, you had to have a blue liquid, certainly can't have a red, because that's too personal. And toilet paper, oof. So, god bless the conservative government, not necessarily Margaret Thatcher, for actually saying, "No, we do need to do it like this". And just like the 2000 year bug, which had a lot of publicity, when the computers were probably all gonna collapse, people said, "Well the HIV epidemic didn't turn out to be as big an epidemic as we thought". Well, that was probably because the advertising was so powerful. Very difficult to measure the two.

[00:07:07]

**INTERVIEWER:** And that's the kind of, like, the uh, the government's sort of perspective on the need to put the word out and to advertise. But what about like, activism within the community and pushing for safer sex?

**PARTICIPANT:** I can't remember anybody talking about— except for the— there was no, I can't recall any official line about safe sex. Obviously from the government, you have, the thing was, "A condom will prevent, the barrier, most probably". Because even then, you know, what about kissing? Something which had just sparked something else off, when Princess Diana shook someone's hand who was HIV positive, that was major news, on all the newspapers, on television. Amazing.

I was in a car accident with my ex-boyfriend, he was in the back seat and I was, we were both pretty pissed, so it was my car but a friend was driving, and he died in the early 90s— we had a major accident, car flipped upside down, blood coming out everywhere, 'cause I'd kneed myself in the nose, and he'd kneed himself in the nose, and that was just before he actually got diagnosed with AIDS and was HIV positive. Gowns, masks, total isolation. Not just a few plastic rubber gloves, this, you know, you got the Ebola virus. So, pretty traumatic.

[00:08:56]

**INTERVIEWER:** And um, that sort of, that leads us kind of into healthcare around that time for people who'd been diagnosed HIV positive, or gay men in general, and how they were treated, and how they received their treatment as well. Is there anything that you could tell us about that, about the kind of like healthcare reception that people were receiving or that maybe you experienced yourself even?

**PARTICIPANT:** When I look back at how I'm perceived, as a gay man, I don't see myself as a gay man. I— people might say, "Oh you're gay, Martin", and yeah. But it's like, I'm 6'4", and I mean some people come up to me and go, "Oh god aren't you tall!" like suddenly it happened overnight and I hadn't noticed. And this kind of like, what a stupid thing to say, "Oh gosh aren't you tall", yeah, hello. [claps]

What I found is, I think, in the gay community, "gay" to a lot of people, and to a lot of gay people, it kind of means sex. I'm going out with a fantastic guy at the moment, he's a young guy, he's Asian, I turn up on my drive at home in the car. My next door neighbour is out, comes out, and he goes, "Oh god, I wonder what they're thinking, I wonder what they're thinking". A. He's Asian, I'm white, you know it's a bit of a white middle class area, and Asians don't mix with whites, you know all that kind of stuff. And I said, "Isn't that interesting? If you were looking at him with a younger person, or whatever, you wouldn't automatically, my guess, go, 'Oh I wonder what sex they're having?' You'd go, 'Oh! Whatever.' Why do I, why do we, tend to think of being gay with just the sex bit?"

So, with the HIV, I think, in a strange kind of way, invite— we've invited in a kind of discrimination, because when there's gay pride, and there's outrageous people parading with almost nothing on, if that was a straight parade, they'd be arrested, so straight people, other people who aren't in the community, my guess is, get the impression— this is my understanding— get the impression that being gay, HIV, is all about sex. Well, what about people who've been, who've exchanged blood with blood transfusions? That was a massive problem, because blood wasn't tested for HIV for a transfusion. Loads and loads of people got HIV who'd probably never ever had sex. So, where I'm coming from is, I think we've got a lot to learn about how I, we, if I could say we, I don't speak for anybody other than myself, put myself, ourself, across to other people. Which then links on to the prostate cancer.

[00:12:39]

**INTERVIEWER:** Would you like to speak about that?

**PARTICIPANT:** Of course I can.

[00:12:40]

**INTERVIEWER:** Go for it.

**PARTICIPANT:** If— d'you want— yeah?

[00:12:42]

**INTERVIEWER:** Yeah?

**PARTICIPANT:** Ok. [laughs] Do you want me to give it an entree, give me an entree, so— 'cause it's a separate subject almost, well it isn't, but.

[00:12:51]

**INTERVIEWER:** So—

**PARTICIPANT:** 'Cause that's where, I've got no problem talking about me HIV experiences, I'm HIV negative as well. But Paul I think wanted me to probably contribute because of the stuff I've done with prostate cancer, and we do talk about sex. Which freaks people out.

[00:13:14]

**INTERVIEWER:** Yeah, yeah yeah yeah. So, I guess, yeah, that's the entree isn't it, talking about sex and how HIV has affected sex, but how other things might also affect sex.

**PARTICIPANT:** Amazingly, any cancer between the navel and the knee tends not to be talked about. Penile, testicular, prostate, bowel, that kind of cancer. I've got prostate cancer. Got diagnosed ten years ago, and being on the autistic spectrum, I tend to ask kind of black and white questions, and give black and white answers. So, what I found was, my surgery and my treatment was so expertly handled, but the consequences of that treatment meant I've got a lot of sexual dysfunction. I've got a lot of endocrine dysfunction, psychological dysfunction. And there was almost zero help on that. So five years ago with Andrew from the LGBT Foundation and Sean from Clapton Bridge and myself, we started Out With Prostate Cancer support group for gay and bi men with prostate cancer, and for trans women. Because a lot of people don't realise, trans women, women have prostates who are trans women, and a lot of trans women don't realise they get prostate cancer.

What I found was, as an example, and I use this sometimes when people ask me to talk about it, I had a radical prostatectomy, where the prostate, my prostate was taken out, I've got a big scar from the top of my willy to underneath my navel, it's about nine inches long. And I had a few— my seminal vesicles taken out, and a few lymph nodes. And I was told that, "Unfortunately we couldn't spare your erectile nerves", so I can't have an erection, but I will be able to have an orgasm. Huh? Orgasm, but no erection. Wow. Couldn't understand that at first, I thought the two were you know, the two came together. And I think a lot of guys don't know that. I as well, didn't know, well what does me prostate do?

Anyway, after three weeks, I was having a shower, still got all my clips in, and I thought, "Ooh, I wonder if I can have an orgasm". So I started to mess about and it's like, "Ooh! Ooh I think I can". Then I got a little bit nervous because I thought, "Ooh, what about if I split all my stitches with the ooh, ooh ooh going on?" Anyway, I pursued it. And I had an orgasm, and it was like, "Wow, I can have an orgasm!" I got out of the shower, dried myself, got on the phone— this is ten years ago as well, so smart phones weren't out— got on the phone, and I text me urology nurse. "Debbie,

I've just had my first wank, this is fantastic!" Got a text back, "Martin, you're the first person who's ever told me that". And I thought, "You're my urology nurse, surely, everybody texts you that". And then I thought, "Well if I'd had my leg off, and I'd run in my first marathon and I text my surgeon, wouldn't he be happy? Wouldn't he say, 'Well you're the 10,000th person, Martin, who's told me that? 'You're the 10,000th patient, thank you, well done!'" And I'm thinking, "This is going to be an interesting journey, if my urology nurse"— god bless her, lovely woman, I hope you know, she knows that, if she ever gets to see whatever she's watching here— shock.

So, that was the start of my journey of, "Let's talk about sex". Doctors, health professionals, don't want to talk about sex. They'll talk about how they've chopped my prostate out, but I didn't know what it was like, not to be in the driving seat. So, which leads me onto a point. I'm 63. I was 53 when I got diagnosed, I was 53 when— just in my 54th birthday when I had the capability of doing certain sexual things taken away from me. I didn't realise, up until then, from the age of 12 or 14 whenever puberty happened for me, probably about 12— I didn't realise, I was on autopilot, I thought I was in charge of my dick, so. When I was feeling horny, guess what, it came up. I thought I made it come up, but it didn't, it came up on its own. Erectile nerves got cut, it doesn't come up. Sometimes the feeling gets there, and it's like one of those telephone exchanges where the operator, "Just putting you through" and it's like, "Oh, the nerve, I'm sorry that's not there anymore, can't put you through, I can't make your dick go hard." And it's like, woah, what's happening.

So, when I was out on the town, using Grindr and feeling horny, because what I found was, I want the chemicals which come with a good orgasm, and it's like, "Oh wow". I've never taken heroin, cocaine, smoked a little bit of dope a couple of times when I was giving up alcohol, I wanted those chemicals. So, Grindr, great. I'm not gonna tell the guy, "I can't get an erection and can't ejaculate" until he's probably got all his clothes off, and then it's like too late, you know, we're almost there then. And of course he'd say, "Yeah I'll be there for 7 Martin", so I take my Viagra, which has got a 40 minute build up time, just to get it right, because that can help me when I'm feeling ok, and an hour would go past, and he'd still not turned up, and I'd text him, "Oh, I'm on my way, I'll be there in another hour", and I'm thinking, forget it, the Viagra's gonna be off, I'd geared myself up to be able to, I've got to get this done, that done, sorted, and then just at the right moment, I might be able to tell you, "I won't be able to have an erection and I can't ejaculate", and it's like, no. Ruined.

Every now and again, somebody did turn up on time. I might have used an injection, you can inject your willy to make it go hard, which freaked me out for nine months but I eventually managed to do it. They turn up, and I told them I can't ejaculate, and I might be able to get an orgasm. So if I did have an orgasm, it's like, "Well you couldn't have had an orgasm, where's the stuff?" So, "Well, I told you, my prostate's not there", and they haven't got a clue what a prostate does, and it's like, well in any case, they're only after sex, and they've probably already gone, already got their clothes on and gone, not looked after what I want, so.

Every now and again there might be somebody who wants a little bit of sensuality, which I discovered when I had some— I had to have extra treatment, because unfortunately when they took the prostate out, my prostate— the prostate cancer had spread, so I had to have chemical castration for two and a half years. So as a man, I

got to know what it was like not to have any testosterone at all, and I discovered sensuality. Which I didn't realise I had, like kissing, and touching, and feeling, and hugging, and the slow burn stuff, rather than the wham bam "let me shoot my load and, oh, goodbye", etcetera. So by not having any testosterone I realised, testosterone is in charge of a man. A man is not in charge of a man. I could relate so much to a woman when, because of the treatment, I was getting hot flushes, because it's like going through the menopause, and they'd go, "Martin you must eat more chocolate, that's what I'd do", and I'd have to make sure I was near an open window, because probably nothing was happening on the face, but I was at 100 degrees Celsius, boiling away, because my hormones were just all over the place. Very relatable to a lot of women, that. Totally unrelatable to men, unless they've had the same treatment, and it's like, "Oh pull yourself together Martin", so. [laughs] I can laugh about it now. Bloody hell.

[00:22:44]

**INTERVIEWER:** Yeah.

**PARTICIPANT:** Here's an example. I mean it's— I'm a smart guy, do a bit of googling, I know where to google, where not to google, and I thought, "It's me endocrine system, I need to find out what's happening with my hormones! I need to talk to an endocrine specialist."

"Hello, can you get me in touch with an endocrine specialist?"

"Why, what'd you need to talk about?"

Eventually, I got through the barriers and I spoke to an endocrine specialist, and he introduced himself, he's probably in his late 60s, "I'm Doctor" whatever", and I said,

"Oh hello, I'm Martin. Could you tell me what your first name is, please?"

"Oh, why'd you want to know that?"

"Oh, I want to ask you some questions as a man, as a man to man".

And he really struggled with telling me his first name. "No, I'm doctor such and such". And I'm thinking, "Ok, here we go again. I want to talk to you, not as a doctor, I want to talk to you as a man, as an experienced GP— not a GP, a specialist, who's been around hundreds and hundreds, my guess, of men with endocrine problems, to see what your experience is of people who don't have any testosterone." He didn't like me doing that. So when I asked him, "Well what's it like for you when you have an orgasm", couldn't cope with that. "Doctors don't ask— answer questions like that, I've got to give a clinical answer", which didn't help me at all, and I'm thinking, "I'm sorry, this just doesn't help me."

That's why— my autistic condition makes me want to ask questions to get an answer. So when people come to the support group and they innocently say— I think they do, I'm sure they— they innocently say, "That was a really good two hours in the support group, that was, Martin", they don't realise how much hard work I do to create the environment where they start to feel comfortable in talking about stuff they wouldn't talk about. I'd been to a number, a lot, of support groups. Cup of tea, biscuit, piece of cake, we don't talk about that stuff. And it's like, well I'm sorry, I do. Well,

um. Now we're gonna get very uncomfortable. Very sweet people, very nice people, don't get me wrong, extremely, extremely nice people. But I'm sorry, I don't— with my autistic condition I can't cope with unstructured social situations, so, I don't want to have a piece of cake and a cup of tea, I want to talk about "How the hell do I get my drug insertion without having an orgasm? Any experiences in the room, folks, can we talk about it?" And what I found is, once I push the envelope, somebody might put their hand up saying, "Actually, that's what's happening to me". "Really? So what are you doing about it?"

[00:25:42]

**INTERVIEWER:** Yeah.

**PARTICIPANT:** Another example. When I was on Grindr, and, I'm monogamous. So when I'm monogamous, I'm monogamous. When I'm not, I'm out on Grindr, Gaydar. "Oh hi, can we meet up?" Really nice looking guy, yeah great. And I started to go, "Ooh, I think I might tell him, I might have a bit of an erection problem", so I thought, "Ok, yeah, driving all the way into Manchester from Burnley, yep, ok."

And he said, "Ooh, uh, I've got a bit of a problem as well."

"Really?"

"Yeah, I cum really, really quickly."

"Do you?" And I said, "I bet you don't say that very often to men on Grindr do you".

He says, "No your the first guy I've ever told".

"Really? Well how about getting together then? I can't cum, you cum easily, let's have a bit of a mess around!"

So we had a great time. So what I found was, by me being honest and knowing what I want, and creating a space where possibly other people might then go, "Ooh, actually..." whatever whatever, sometimes, not saying always, sometimes that creates a fantastic space. We had a great time for three hours. Next. [laughs]

[00:27:06]

**INTERVIEWER 2:** Um, yeah.

**PARTICIPANT:** Should I answer you, or keep— I'll talk to Millie.

[00:27:09]

**INTERVIEWER 2:** Is that ok?

**PARTICIPANT:** Yeah.

[00:27:11]

**INTERVIEWER 2:** What— so you mentioned earlier about that people don't want to talk about certain kinds of cancers below the navel above the knee, yeah? Could you talk a little bit about that, and where you think that stigma and shame— I mean in some sense it's obvious, but if you could talk about where the sense of shame

comes from and how that manifests maybe in the group, then maybe also what impact that has on people being able to get— have the conversations that they need to have, or get the services that they need. So maybe, yeah, we could talk a little bit— and here's the street cleaner. [laughs] Um, talk a little bit about the group and the kinds of things that come up for people in the group, protecting confidential— maybe not naming individuals.

**PARTICIPANT:** No of course not, of course not. And I won't say anything where anyone could know it was talking about— well obviously I've talked about Debbie, but she's alright with that, I've mentioned it with her loads of times. If something like that does happen, you stop me and I'll start again, so.

[00:28:20]

**INTERVIEWER 2:** Ok.

**PARTICIPANT:** Right. What I've found about prostate cancer, it's a cancer which hovers between the navel and the knee, and in my experience, anything medical which is between the navel and the knee tends not to be talked about. So for instance bowel cancer, even not being gay, you know, that's definitely a no go area.

Besides prostate cancer, testicular cancer— in younger people, prostate cancer tends to be a cancer which is in 60 to 70, 80 year olds, but getting more and more diagnosed in 40 year olds, so you know, if a 40 year old's gonna live for another 30, 40 years, getting their sexual function and libido back is quite important. What I found is, being a man gets in the way of being a man with prostate cancer. Being a man with testicular cancer. Because, it's about— and I've thought about this a lot. In the olden days of the NHS, patients used to be treated as "the kidney". The person's in the bed, and the doctor would come and examine "the kidney", rather than, "Oh hello, Mr Brown", it's like, no, you're the kidney. And it's like, I'm the prostate, I'm the seminal vesicles. And I've thought about this. When I come down my stairs, and it's a bit chilly, I turn the thermostat, which is on the wall next to my stairs, and the temperature comes up. Actually, it's like, if the surgeon took away the thermostat, what's behind the thermostat? The boiler, the radiators, the water, the electricity, the pump. And it's like that, that's how I imagine it. They've taken my thermostat away, my prostate, and that's all they're gonna deal with. Well, the central heating doesn't come on anymore because it doesn't switch it on, and it's the same with me prostate. I'm sorry, but my libido doesn't switch in any more, I can't get erections, "Oh no no no no Martin, we've got, we've done a fantastic job of getting rid of my thermostat, you can't see where it was, it's been plastered over and painted, you can't see any—" Fantastic. But I've still got all the plumbing the other side of the thermostat. [whispers] But we don't talk about that.

[00:31:05]

**INTERVIEWER:** Yep, yep. And is that something that through like these group situations that you mentioned before, does that come out a lot? Does that reflect the experience of a lot of people, do you think?

**PARTICIPANT:** It's interesting to be in a group of— a prostate cancer support group, any group really, but if the group's kind of pushing the envelope. At the age of 14 when you did O level biology or biology at school, the man gets an erection, inserts it into the woman's vagina, ejaculates, the egg is fertilised, ok lads your job's done, put you away, now let's go to the woman and the baby. Very important, don't get me wrong, it's all going on and the baby grows, this that and the other gets born. Boys, we don't have a language to talk about what goes on for us. My guess is— I've never been a girl, right? My guess is at the age of 12, 13, or 14, periods start, blood comes out every month, people lose continence and wet themselves possibly and have "women's problems". Boys don't have "boys' problems", the only boys' problems we have is bragging about how big our dicks are. That's the only problem we have.

So when our plumbing gets all messed about, I don't know how to talk about it!

[00:32:36]

**INTERVIEWER:** Or find the language.

**PARTICIPANT:** I haven't got a language. So, we're kind of have to invent the language, and a lot of the time, and the language isn't the kind of language which medical people want to hear. So, when I got interviewed, like I'm getting interviewed now, and it was for a hospital, there was big controversy when I said the word "wank". And it's like, yeah but that's the word people use. I'm not, you know, talking about kidnapping babies and how I dissect them, you know which is pretty gross. It's like, every boy has a wank. So, what's the problem? So even the system suppresses the language I and others want to use. "Oh I masturbate". Oh yeah, can you hear that being said in the playground when you're a 14 year old? "Excuse me does anyone masturbate here?"

So, in the support groups, we explore the language. "So what do you mean by wank?" Now for instance, some of these interviews are about, let's talk about sex. What do we mean by that? What if on the poster it said, instead of "let's talk about sex", "let's talk about sensuality"? Ooh. Ooh. Now, before my op, "What'd you mean by that, kissing?" I don't have that language. Now I've had no testosterone, now I can talk about sensuality. I've experienced it, I've got the language of it.

So what I've found is, the— when people know how to talk about it, that opens up such a big arena for them, and they get in touch with so many other things they've never explored before. But if you try and talk about that with the same language to others who can't use that language, it's like saying, "Could you please think of something you can't think of? And that's what we're gonna talk about." Straight over their head.

[00:34:48]

**INTERVIEWER:** Yeah, yeah. Matt, do you have any questions?

[00:34:53]

**INTERVIEWER 2:** Um, yeah. You... you talked about the "Don't die of ignorance" campaign, and you also talked about how even if medically they're not related, dealing with HIV and the kind of stigma around HIV but also the kind of— you said that HIV and prostate cancer have been related in a way in terms of maybe more the—

**PARTICIPANT:** The perception.

[00:35:28]

**INTERVIEWER 2:** The perception and also, stigma, shame, also then a psychological impact and I was wondering whether you could talk about that more, that side of things.

**PARTICIPANT:** My take on that, my take on that.

[00:35:39]

**INTERVIEWER 2:** Yeah.

**PARTICIPANT:** I've had two— three very very close people die with AIDS. And now I've got prostate cancer, I've had prostate cancer for the last ten years. I've got great respect for people who are HIV positive, and the traumas they go through. If— and it, prostate cancer is the biggest killer of men. If as much research had been done on the psychological impact of prostate cancer as it had been with HIV, what a tremendous difference that would have on the quality of life of men— gay men, straight men, bisexual men, trans women— who've got, been diagnosed, living with prostate cancer. Unbelievable. To me it's like, if I go into a Macmillan resource centre, a big one, not like a little stand in a corridor, but a big centre, big room— like at the Christie Hospital— there are cabinets of wigs, prostheses, places to go in town for where women who've had prosta— sorry, women who've had breast cancer and get support and it's talked about. And I think, "Well, where's the cabinet for me? Where's the thing on cock rings, or electrical stimulation, or penile pumps, or injections, or whatever?" Ok, if it's that scary, have it in a smoked glass cabinet where we'll get the key and you can have a special viewing, Martin, you know? Not even that. So, there's very little support.

Now, and I think yeah, my ego's gonna kick in a little bit on this, innocently one or two people will say, "Oh this is fantastic resource you ought to look at Martin, for Prostate Cancer UK, or this that and the other— it definitely talks about the psychological affects." Uh, yeah? If you have a look at it, I'm actually in the video. I actually happened to make that. I pushed PCUK to make videos like that, to bring literature out which says things. I'm invited to comment on their literature, is it inclusive. And for instance, the latest literature says, you know, "Girdle up your loins, go to your health professional, talk to your health professional about your sexual needs" and I say to the publisher, "Hang on a minute, you're assuming your health professional knows what he's gonna talk about! If that's the first time I've actually talked to a health professional about my sexual needs and I get a rejection, if that's the standard I think it's gonna be, and I don't know any different, I'm crucified." So hello folks, so me and a few other people get to peer review the literature and say, "I

think you ought to have something in there about, you need to check your doctor out, if he is comfortable, or she, in talking about what you want to talk about. And if they're not, find somebody else. Don't give up, this is your prostate cancer. This is your HIV. You know? Don't take things on face value." I'm not saying you shouldn't, but you know, I'm the only one that's interested in my prostate cancer, ultimately. I'm just a number, effectively, in the system. Don't get me wrong, there are some very, very, very caring people, please don't think I don't think of them as caring people. But I'm a statistic. They don't know whether whether my prostate cancer is gonna kill me next year, or in 20 years' time. I'm a statistic. "If you have this treatment, Martin, statistically, you should survive for another ten years." I might die in six months, I could live for another 30 years. Oh you see me getting all worked up there. [laughs]

[00:40:12]

**INTERVIEWER 2:** I was gonna ask another question. You've mentioned how, in a way your experience with cancer has changed— with prostate cancer has changed your view, in a way, of what sex is or could be—

**PARTICIPANT:** Of what?

[00:40:32]

**INTERVIEWER 2:** Of what sex is—

**PARTICIPANT:** Oh right.

[00:40:33]

**INTERVIEWER 2:** —or could be. Which is really interesting. I was just wondering, like, you have given us a few snippets, but how you've navigated your... How it's shaped how you navigate your sex life in a way, and how you negotiate sex—

**PARTICIPANT:** Yep, I've got it.

[00:40:59]

**INTERVIEWER 2:** —and what you're looking for, and desires, essentially as well.

**PARTICIPANT:** The nitty gritty.

[00:41:05]

**INTERVIEWER 2:** Well, if you're up for it.

**PARTICIPANT:** I'm all for it. It's a really good question. I've been going out with a really sweet guy, and he's Asian, and no way would I ever, on camera, give away who he is, because being Asian and gay is a big no no. Anyway, such a sweet guy. Monogamous, trusting, I'm monogamous, I'm trusting, we have a great time together. I've had past relationships where that has not been the case. People have said, "Martin, you know, I'm with you 100%", there's a part of me that's thinking,

"Something's not right here" and I found out they've been cheating. I could put my hand on my heart and say I've not done that. So, with my partner, let me say, with my partner, I can't believe— sometimes I just can't believe how he accepts me for how I am. And also, the surgeon who did my radical prostatectomy can't believe what I told him a few years ago. I told my surgeon, "I can get erections on my own now— ok, with a little bit of help from Viagra, but I don't need to put an injection in", and he said, "You shouldn't be able to do that, Martin, because we cut enough nerves so you can't do it". Well I reckon, my brain and my libido, my inner soul, is so comfortable now, that what I've seen in— as a healthy male, if there's a part of me that doesn't believe I can get an erection, like really doesn't believe it, I won't get an erection. Called erectile dysfunction. So healthy men have erectile dysfunction. When all that autopilot got taken away from me, even the slightest smell of "I won't be able to get an erection", that totally would never ever happen, so it's even more sensitive.

So now, because I'm in such a caring, loving relationship, and it's not a problem if I don't get an erection, I get an erection! Ok, it's not as what it used to be, but I'd say it's 90% of the way there. And strangely, and I still have difficulty with this, so it's my stuff which is going on, when my willy's a bit floppy and it doesn't do what it's supposed to do, it turns him on! And it's like, I kind of don't want to believe you, that it's turning you on because, and I suppose that's just my stuff, because, well that wouldn't turn me on, but ok. Believe him, Martin! It's turning him on!

So, what I've seen is, as I've been exploring who I am, and I've been developing my language of exploring who I am, I get to see who I was and who I can be. And, what I've seen is, my shit just gets in the way so many times when I have to be in charge of it. When, uh... a million years' worth of evolution has given me some autopilot, I didn't realise I was autopilot when I didn't have to worry about it. When I felt horny, I got an erection. So, when I meet up with my partner, and in fact after our chat now I'm going over to Liverpool and meeting up, I've not seen him for a week, I've got one of my little shields, my tenner shields[?] [00:45:04] in, a little tenner pad for men, that's another interesting thing, they're "engineered" "for men" [dramatic voice] and they're black. Now, they're not poncey, white or pink, fluffy stuff, you know where a woman is walking to the door and she's meeting her friends, this is "engineering". Anyway.

I'll give him a hug and I'll say, "Oh! I've just had a bit of a wee". That turns him on! Because he knows I'm getting excited about being with him. Now to a man to be incontinent in any way, real big no no. "I'm gonna smell of piss, and all this that and the other, and I've never experienced it before". Whole new dimension.

When I wasn't going out with my partner, and I was playing around on Grindr or whatever, and I was chatting to my mates, and I said, "Oh god, I climbed over this one guy, like getting over the other side of the bed, I got a bit excited, and I sort of wee'd all over him." And he said, "People have paid good money for that! What are you worried about!" And I thought, "Yeah, it's just my shit." So, my stuff gets in the way so many times, which is probably... my— the way I've been brought up, you know. I remember asking my mum— my dad had been dead for some time— and she said, "Well what do you do when you're gay, I don't really want to know". I said, "Mum you're pretty screwed up about sex in any case".

"No I'm not".

"Well did you ever give dad a blow job?"

And she looked at me and said, "What's that?"

And I said, "Oral sex" and she was convulsing and nearly sick, "Oh my god that's disgusting."

And I thought, "Poor old dad, never had a blow job, probably."

So, that's my kind of inheritance, so it's my stuff which is limiting me. And compared to my three brothers and sister, I'm really the weird one, oh my god, oh my god. Uncle Martin's talking about stuff we don't talk about. And it's like, "Oh god, I wonder what you're like [laughs] in bed. Anyone."

[00:47:13]

**INTERVIEWER 2:** Just on that, do you feel like attitudes are changing, like or have you been able to have conversations with your family or, then more widely in society do you think attitudes are changing toward talking about things that involve, yeah, sex, the genitals, sexuality, sensuality?

**PARTICIPANT:** I'll give me long answer: no. No. In fact I think about how people talk about sex now. When I'm around people— and I hope I'm conscious and sensitive to this, but it's what I've observed anecdotally. When men have been just diagnosed with prostate cancer, just like when I was diagnosed, my top 100% concern was, "Am I gonna live". Sex did not enter my thought.

So if I'm in a support group and I wanna talk about sex, because I've handled my "Am I gonna die" and someone's just turned up, "Oh I've just been diagnosed", it's not appropriate for me to, "Oh, how's your sex life?" It's just not. Anyway. What I've found is, when the "I'm gonna die" bit is kind of handled and it's reasonably ok, they're not gonna die, they're not getting to grips with the side effects, they just don't know how to talk about sex, generally speaking. Anecdotally as well, this is my evidence. Just like me, they would be, suffering might be the word, from how they were brought up with it. Suffering from not having the language available to talk about it.

So even though they might have been active out there on the scene, and isn't it strange— if I was on Grindr, I would share the most intimate secrets: "I want you to tie me up, I want you to do that with the dildo, I want you to do that with my bollocks, I want you to do that with that", but I won't talk about anything to my doctor. But I'll say that to a complete stranger. And then if somebody took a photograph of that happening, without me knowing, and then presented it to me in a public place, I'd be mortified! Why would I be mortified? I did it, it's like before I came out, I'd hear in the background people saying, "Oh, you don't want to mess with him, he's a poof", this is at work, you know, when I was not working for myself and I was at work BAYUN[?]  
[00:50:00] and I'd get really upset about it. Then I thought, "But I am a poof. Why am I upset? It's the truth." I was upset with my truth. It's my shit that I'm upset with. Did I get handcuffed, gig I get screwed with a dildo, did I—? Yeah. With another person in the room? Yeah. So what's my problem? My upbringing, my values I put on that kind of thing, in a certain situation. Yeah, not appropriate to talk about things like that to a five year old, to a ten year old, to a 16 year old, you know? Yeah, be appropriate, but

I find, people is just as messed up now as they were before. Just because I can go out and buy a condom from a machine in a sweet shop, hasn't given me the language, it just means I can have unconscious sex easier. From a— in fact, it might have made it worse, in terms of having a good dialogue with other people.

So if I wanna talk about sex, is it about the, "Can you get your kit off quicker than before?" Yeah, that might happen, but does that actually mean what we want to talk about? If it's a quick wam bam thank you ma'am, go out and get it[?] [00:51:22]. When I came out in the 70s, it took me six weeks to find someone, I answered a box number on the back of Zipper magazine, sent me letter off, it got stored for a week for all the other letters to come in, they get posted to the bloke who put the advert in. He kind of read 'em and thought, "Yeah, I might respond", and then I might get a response back. That's how quick I had sex. Obviously I could have gone cottaging, but I didn't even know about that. Now, I could have sex within ten seconds! Switch me mobile on, get onto Grindr, "Ooh wow, there's somebody 20 foot away, yeah, there we go, thank you". Does that mean I'm really talking about sex? I don't think so. That's my long answer.

[00:52:07]

**INTERVIEWER 2:** Ok, great. So we're coming to the end of the interview now, is there anything else that you'd like to add that we haven't covered, anything else you'd like to mention before we finish?

[pause] [00:52:24]

**PARTICIPANT:** I was born in 1954. My dad died in 1981. His dad— and my dad was about 53 when he died. His dad who I never met, died in 1941, at the age of 48. When I remember my nan, who died in 1981, my dad's mum, I remember my nan saying to me, "If your dad ever hugged me and kissed me in public, I'd die." And I thought about that, and I'm thinking, that is an instruction, an instruction to your child: "If you show any emotion to me, you will kill me." I was brought up in the Victorian times. I can't imagine how my nan had four sons, she had four kids. My mum had five kids, my mum and dad had five kids. My mum told me, she only know on her third child how children came about. She didn't know how it happened. She probably thought, rubbing navels did something, or kissing did something, and when I asked me mum about giving a blow job to me dad, she didn't know what it was, she was mortified that I'd mentioned it, and I thought, "Wow, what kind of sex did my mum and dad have?" You made your bed, you sleep, you lie in it, you get on with it whether you have sex or not.

So, I'm thinking, how much have we really moved on since Victorian times? Which is in me— which is in me at the moment? I think it takes a long time for a language to get developed so we can talk about something other than sex: sensuality, connectedness. What I see out there now, on the planet, is we're getting less and less connected, even though I can hold up a bit of technology and say I'm connected to four billion people, I'm not really connected, it just means I can have sex quicker. But am I actually communicating with them better? I don't think so. That's my take. So is anybody seeing— looking at me in the year 2075, I didn't have any kids. I've got lots of st— [audio cuts off]

**[00:55:08] End of transcript.**