

## Speaker Series – *Fighting for our lives* with Nick Cook, Robert French and Dr Shirleene Robinson

**Interviewer:** [00:00:00] To begin, I'd like to acknowledge the traditional owners on the land on which we're recording today, the Gadigal and the Wangal people of the Eora Nation and pay my respects to elders past, present and emerging. Welcome to the Inner West Library Speaker Series in honour of World AIDS Day. We reflect on the community response to the AIDS epidemic in Australia and how community advocacy has played a role in placing Australia as a world leader in AIDS education, prevention and treatment. Joining the conversation is Nick Cook, Robert French and Shirleene Robinson. Nick Cook is the author of *Fighting for Our Lives*, which is the inspiration for the podcast today. The book chronicles the community response to AIDS in New South Wales from the 1980s to the year 2000. Underpinning this history is the formation of ACON, New South Wales leading HIV and sexuality and gender diverse health organisation. Robert French has been described by the *Star Observer* as a community hero. His activism includes serving as convenor of the NSW Gay and Lesbian Rights Lobby and was vice president of ACON in 1986 to 1987. He's the author of a number of publications which include *Gays between the broadsheet*, *Australian media references on homosexuality 1948 to 1980*, and *Mozzie's Could Spread AIDS: Australian Media References on AIDS from 1981 to 1985*. Shirleene Robinson is a leading historian. She's the author of *LGBTIQ Australian History*. In 2018 she curated an exhibition titled *City Response to Crisis: Volunteers and the HIV and AIDS epidemic in Sydney from the 80s and 90s*. She's the author of many publications, including *Gay and Lesbian: Then and Now*, *Australian Stories from Social Revolution* and *Yes, Yes, Yes, Australia's Journey to Marriage Equality*. She's currently the senior curator of oral history and indigenous programs at the National Library of Australia. Welcome, everyone. Nick, I'd like to start by asking you, how you came about to write *Fighting for Our Lives* and what you've discovered in writing the book?

**Nick Cook:** [00:02:16] Well, it actually began exactly a decade ago when I was working for a magazine and I wrote a story on 25th anniversary of ACON. I was stunned that nobody had told this story before. It just was not spoken about. Nobody talked about it. It just wasn't, to us HIV was this dark, hidden thing in the cupboard that might jump out and grab you, but it wasn't even that scary anymore. It just meant you would

have to take some pills for the rest of your life. And the entire story had been lost. That just stunned me. And I really did not like that, because, it's not that long ago. We're not talking about ancient history. We're not even talking about World War Two. I mean, well, Robert French is here today, he's not a very old man. And he was there at the absolute heart of it. He was there at the centre of it. He was there at the funerals for many of these heroes. And so there was just a need for this story to be told, as time went on and it became clearer and clearer that nobody else was going to do it. That's when I stepped forward and wrote the book, and it sort of went from there.

**Robert French:** [00:03:19] I think part of the reason for that Nick, is that it's very hard for us - those of us who were there at the time - to conjure up the dread and the fear and relive those particular times, having gone through it. And I suspect that lots of people just wanted to put it behind them because it was such a difficult and awful period in Australian history.

**Nick Cook:** [00:03:44] Oh, I couldn't agree more with that. And also, to be honest, maybe it's an a critical the way I was saying about the fact that nobody was writing it, I think it did actually need somebody from the next generation to look at it with objective eyes to see it properly, who who wasn't involved in the middle of it. I think that was an important part of it too. And, what I learned out of it was, well, first of all, I knew it was going to be, I knew it was all about death and dread and homophobia and violence and all kinds of awful things. But what stunned me was the strength of the community response and how that part of the story had not been told properly. Australia's response to HIV AIDS is one of the best in the world, arguably the very best in the world. And, the doctors get a lot of credit for that, and the politicians get a lot of credit for that, and rightfully so. But what was missing was the community response, the community part of that. And that is what really made it the best in the world. I mean, gay men were the ones who were most at risk of this. Now, this is at a time when doctors had only just decided that homosexuality wasn't a mental illness, and many politicians still thought that homosexuality was a crime. It needed the community, it needed them, it needed them to get together and gather together a group of people who could be trusted by these gay men in the bars who had this deadly disease coming at them. They needed somebody that they could trust and that would work for them and that really had their interests at heart. And they also needed somebody to get together and form a

really strong group that could bash at the doors of the politicians and the doctors and say, hey, get together, let us in, let us help where we've got to do this together.

**Robert French:** [00:05:37] I think there are two things to add to that. Firstly, you've got to understand, particularly in New South Wales, where we were in relation to homosexual law reform. We hadn't decriminalized gay male sexual behaviour. That wasn't done until 1984, despite three attempts in the New South Wales Parliament. So, one, there was a great deal of anger on the part of the gay male community anyway, against politicians and against the fact of continuing discrimination factor is that we really didn't know early on what this damn thing was. It was given an unfortunate name of GRIDIS - gay related immunodeficiency by United States doctors - which seemed to give some indication that it was it was genetic to gay men, because nobody quite understood what we were dealing with and the community didn't. So there was a bit of anger there. The first time that we started to get some sort of breakthrough and begin the relationship with the medical profession was actually in August 1983, where at Paddington Town Hall in Sydney, there was a large gathering of doctors and gay activists, where the doctors I think, for the first time, were confronted with this anger, and also began to realise that in fact the days of the "doctor knows best syndrome" were gone. They were not going to be the way to deal with it. That wasn't an attitude to deal with the public infection that we had. There'd been a misstep earlier in the year when the blood bank quite rightly decided not to allow gay men to donate blood because we weren't quite sure what was going on. But it was so badly handled that in fact, it led to a lot of anger, which then led to this public meeting. It was only from that point onwards and a number of the doctors who in fact have acknowledged this, Professor Penny from St Vincent's Hospital and the University of New South Wales. When Lex Watson was dying, he was one of the activists that was most at the forefront in the early days, sent a note to Lex saying, thank you for teaching me about your community. And that's actually happened from that August 1983 meeting.

**Nick Cook:** [00:07:50] And it's actually one thing to add to that as well, is what Robert mentioned about that blood bank ban. That was the very beginning of the community response because there was a protest against by by gay men against the ban on the blood bank. It was actually a terrible idea. I mean, it's still argued about today. I don't want to start that argument again, whether or not they should have

protested against it because it was the right thing to ban gay men donating blood at that time. But the protest was the very beginning of this community response.

**Interviewer:** [00:08:24] With that, throughout the book, there's a lot of community demand to be at the decision making table and on all sorts of aspects of the crisis, from education to treatment. Can you talk a little bit further about this and maybe what some of the legacies in community health have shaped from this?

**Nick Cook:** [00:08:43] Well, it's just it just changed community health. I mean, it just never happened like this before. It first began in New South Wales, and it was Lex Watson gave a great quote about it because he said "They'd been bashing on the doors at Macquarie Street for months and years saying, let us in, let us in, let us in." And Neville Wran just refused to speak to them. And then AIDS came along and they said to the Health Minister, can we come and speak to you? And he said, "yes, what time?" The health committee was set up and three gay men from the community group was allowed to be part of that. And this was the very first time in Australian history where first, well, certainly gay men were allowed to be part of the decision making process. But more than that, to the affected communities, previously, it would have just been the doctors and politicians. This just changed. It changed forever, the way health was done. And now you see the same thing today with, well, with everything. You'll see it with indigenous communities or people with autism or it's no longer a case of the doctors telling them what to do and telling them how it's going to be treated. It's a case of the people affected by whatever it is they're talking about, are now part of that decision making process. And that began with that with that HIV AIDS response and with those gay men. It of course went on too. It wasn't we talk we talk mostly about the gay men because especially in Australia, they were most affected. But of course, it applies also to sex workers and injecting drug users. But it was the gay men where it started.

**Robert French:** [00:10:20] Particularly sex workers. I mean, that's one of the real positive stories that came out of it. Very few sex workers ended up with HIV infection, and that was just brought about by the sex workers themselves, the Prostitutes Collective, working with government and a government, allowing them in, negotiating with them.

**Nick Cook:** [00:10:37] And one of the facts from my research that just really blew me away. Did you know there is never, ever been a single recorded case of anybody contracting HIV from a female sex worker in Australia? That's how successful this was.

**Interviewer:** [00:10:52] And amongst all the success, it wasn't all smooth sailing with all the lobby groups was it? In your book you talk about the sometimes strained relationships between some really great organizations such as ACON and Act Up and the Bobby Goldsmith Foundation.

**Robert French:** [00:11:07] Well, there were certainly egos on both sides. I've got to say that even amongst the doctors, there were egos and there were little fights on their little committees.

One of the unfortunate things, I think, in New South Wales, unlike other states, is that a whole lot of other groups formed before the AIDS Action Committee formed, and therefore you ended up with turf wars, which I'm sure Nick can talk much more authoritatively about than I can. But you ended up with those sort of turf wars amongst the various groups, whereas that didn't happen in other states. Everything came under either of the AIDS action, like the Victorian AIDS Action Committee, which became the Victorian AIDS Council. Whereas ACON, when it got formed, it then had to negotiate with these other groups. And government was important in that, quite rightly, Neal Blewett said "I'm going to deal with one group in each state. Get your act together."

**Nick Cook:** [00:11:56] And Robert's hit it exactly on the head there, that's exactly what it was that I mean, you had, the Bobby Goldsmith Foundation was raising money. The CSN was caring for them. One group would be dealing with the politicians. One would be dealing with the doctors. And that was a real problem because, and that's actually where ACON came from. Exactly what Robert said. It's like "We have money to give you, but I'll tell you what, we're not going to give it to all of you and we're not going to let you fight over it. You get together and form one group and that's it." The important thing to remember is this, it is, that, this is life and death situations. And so the passion was through the roof. And, yeah, the fights were vicious. The big lesson I took out of this, it is for community groups to have very clearly defined roles of responsibility and very clear relationships between each other, of what they're going to do and how they're going to do it. Wherever there was trouble, it was where those kind of things happened,

where there was that opaqueness, that lack of clarity between who's doing what and how.

**Robert French:** [00:12:58] There was also very early on with some of the groups a distrust of government. And there was this very American attitude that we'll look after our own. We don't need government involved in this. This is in the early days before we realized just how terrible an endemic it was. It was a wrongheaded attitude, but it took a lot to in fact, convince those people to come into the tent.

**Nick Cook:** [00:13:20] Oh, absolutely. There was that real philosophical kind of idea of what is a community group going to be. And there was a big, and it was a real argument, and it wasn't this was not so much about the egos and whatnot. It was, are we going to be a frontline service provider with government money actually doing the job? Or are we going to be independent from government and stand back and let them do the job, and we're going to advocate about how they should do it. They obviously went with the other, we'll take the money and do the job. Now, the trouble with that of course is, once you're in the government's pocket, it makes it much much harder to, tell them what to do, because they can take that money away from you. And that actually happened with the prostitutes. But they got around that with people like Bill Whittaker. Actually, there was a genius move that they came up with, was that ACON stayed in the government pocket and said, "Oh yes, we're friends with you, we're happy with you. But then, of course, on the other side, they helped set up Act Up, which was this vicious, wild, protest movement, that at one point they invaded Parliament House and leapt from public gallery onto the floor. I mean, they did all these kind of things. And, of course, ACON would say, "Tut, tut, tut, how dare you? We don't agree with that. We want to talk with the government." But of course, behind the scenes, ACON was cheering for it. So they found a great way to do both of those things.

**Interviewer:** [00:14:42] Shirleene, I'd like to bring you in here. You've researched the Queensland experience, which is quite a different political environment to New South Wales at the time. Can you talk about this and the unlikely alliances that emerged?

**Shirleene:** [00:14:54] Yeah, absolutely. So, I think you're right to say Queensland really is quite different to what's happening in the southern states, and, probably one of the most important things to remember is that, during this period, male

to male homosexuality was still illegal. So Queensland didn't decriminalize same sex acts until 1991. Unlike New South Wales where, decriminalisation happened in 1984, Queensland really did become the epicentre of a lot of prejudice.

One of the cases that most people would probably be aware of was when three babies died in Queensland after they received blood, which had been donated by a donor who, didn't realise that he was HIV positive, a young gay man and a fourth baby later died as well. This really focused a storm of attention on Queensland. And of course, at this time, you also had Joh Bjelke-Petersen in power, incredibly hostile to homosexuality. I think he's many quotes that he's put on the record about gay people being disgusting, depraved animals.

He denied that there were any gay people in Queensland. If there were they must have just come over the border from New South Wales and so on. So you had this hostility where, in the other states, state governments worked very much hand in hand with the Federal Government, whereas in Queensland, the people who are involved with the Queensland AIDS Council had to receive money, which was given to them by the Sisters of Mercy. So the Sisters of Mercy received money from the Federal Government and then they gave it to the AIDS Council. There's a really famous quote that's been used, and I know, I know, I've spoken to Sister Angela Mary who absolutely loves this. Neal Blewett described the Sisters of Mercy as "the most cheerful of money launderers for their actions." But, in terms of them passing money on to the AIDS Council, that was, not without risk, because they did administer three hospitals in Brisbane, and if their actions had been discovered, those hospitals risked state defunding. So, the Sisters of Mercy, a Catholic order of nuns, really did provide very strong support to the Queensland AIDS Council in those early days. And I know that a number of other religious organisations did as well. St. Luke's Nursing Sisters and so on. So I think Queensland is a fascinating case study for us to talk about.

**Nick Cook:** [00:17:14] Do you think the government did know and turn a blind eye? Or were they really ignorant of what was happening?

**Shirleene:** [00:17:19] I think that Joh Bjelke-Petersen was absolutely ignorant to what was happening. The question of whether other people knew, is an interesting one. I do know that, and Bill Rutkin, who I think is one of the true heroes from this period, the

longest serving President of the Queensland AIDS Council, he managed to register the Queensland AIDS Council when Joh Bjelke-Petersen was away, out of the state doing his Joh for PM campaign, he was tipped off that Joe was away, and that his best chance of getting the organisation registered was going to be at that point. So, the government overall was very hostile. But, you know, there were the odd person that would be supportive in some ways.

**Interviewer:** [00:17:58] Shirleene, you've also focused your attention and research to the role of the community support network during the peak of the crisis. Can you tell us about this network and the importance of capturing the stories of volunteer carers?

**Shirleene:** [00:18:12] So the community support network is a great case to look at. It was established in September of 1984, by a group of gay men who had experience in nursing who then went on to train others to provide home care for people who were impacted by HIV and AIDS. And Terry Goulden played a leading role in that. By 1985, it had come over to ACON. Just to give you some indication of the scale of care that was provided by CSN, Jennifer Power, who's written about this, has estimated that during 1990-91, staff and volunteers provided 11,874 shifts for 173 clients, which amounted to more than 72,000 hours of care.

**Interviewer:** [00:18:54] Shirleene, would you be able to expand on the role of women in the CSN?

**Shirleene:** Certainly women as carers in organisations like CSN and Ankali, that's really important to know, and also the contribution of women in other places outside of New South Wales, like Queensland. They do play a significant role. I do want to acknowledge the position of women with HIV or AIDS, and I think probably one of the most stigmatised and well-known women to talk about would be Sharleen Spiteri, who appeared on *60 Minutes* in 1989. She was, she was fairly honest about her position as a sex worker. She said that she tried to get her clients to use condoms, but they would not always do that. Essentially, you had a real outcry sort of come about, as a result of her making that statement. She was forcibly taken by police from her flat. She was detained for weeks, and she spent the next 16 years under 24 hour supervision by health workers. And she died in 2005 and she was still under a public health order at



that time. So I think just that gives you a sense of the stigmatisation, particularly of visible sex workers who were HIV positive and that this is a really sad case.

**Interviewer:** [00:20:10] And Nick, you documented this in your book, don't you?

**Nick Cook:** [00:20:13] Oh, yeah. I talk a lot about Sharleen. I just found that horrifying. I just couldn't believe it. She did not handle the situation well herself. She clearly had some significant mental health issues. But no, what happened to her was appalling. It was the most, one of the most disgusting examples of scapegoat journalism I've ever seen. And just these two massive storm clouds of terror about HIV and stigmatisation of sex workers. Sex workers copped it probably worse than gay men because they were really seen as the bridge to infecting the decent community, the nice people. If one of our husbands or sons accidentally steps across the line to one of these sex workers, well, that's it, we're all going down. And what happened to Sharleen was just appalling. ACON actually had a lot of, we'll we're back to Bill Whittaker. I think at one stage he was hiding her in his office. If I remember correctly. They tried to help it. Like Ruth Cotton. She was had a very, very hard position to be in the New South Wales Health Service. And at one point in one of the hotel rooms, they were hiding her from the media. She tipped a bucket of ice over Ruth's head. So, it's a very, very complex story. But no, ultimately, the way she was treated is just disgraceful.

**Shirleene:** [00:21:27] Yeah, I think it was a very obscure provision of the Tuberculosis Act or something like that that was used to detain her, but, I mean 16 years under 24 hours supervision, obviously not the best way to go about things, and I think a complex but really sad situation.

**Nick Cook:** [00:21:42] Appalling. And she actually became the most expensive patient in the history of New South Wales health. One of the people I interviewed went and saw her three days before the end and she couldn't get out of bed. She could barely move. She was well, she was clearly about to die from these HIV related illnesses. There was that guard still watching her. It was just appalling.

**Robert French:** [00:22:01] I actually wanted to say something positive about the contribution of women to the whole thing. The nurses within the hospitals - mostly women - not exclusively so, but a lot of women served on AIDS wards in St Vincent's

and in RPA. They became sometimes the conduit between the patient and the doctor, particularly doctors wanting to get people out of the ward and say send them home to continue their medication. And they also became the supporters of partners of gay men against the families. It's a role that Paul van Reyk, I think, is actually talked about and written about, but in fact, it's one that hasn't been fully explored either.

**Interviewer:** [00:22:40] Robert, now I'd like to turn to you regarding painting a picture of what it was like at the time.

**Robert French:** [00:22:45] Well let me tell you the story about myself and my partner. My partner was diagnosed in 1993 just as I was about to step on a plane to go over to Washington on a two year contract to work with the World Bank. Was I to go? Was I not to go? In the end, I was told by Laurie my partner, that I had to go. I returned in 1996 to Australia, to take up a job here. And later that year Laurie had his first seizure, and over the next five years, it was an increasing number of visits to hospital, coming out of hospital, going back into hospital, three bouts of lymphoma, the final bout, and his brain actually is what killed him. He kept bouncing back, and was determined, bugger, we the family should refer to him as Lazarus. I do remember him having a seizure in the car sitting beside me as I was – thankfully - I was driving up Burton Street in Darlinghurst and just put the foot down, went through the lights and ended up in emergency. This is about eighteen months before Laurie actually died, and on one of the visits to the hospital - and he was in such a dire circumstances - I remember coming back to my car one night after visiting, and this tune from the 1950s – it's an old Jo Stafford number – called *Maybe*. "Maybe I'm right. Maybe I'm wrong. Maybe I'm weak. Maybe I'm a strong. Nevertheless, I'm in love with you." And this just kept playing in my head, and I sat down, in the car behind the steering wheel and I just burst out crying and sobbed, for the next two or so minutes. I just, I just couldn't stop. It was the beginning of my grieving. But that's the sort of experience that it's not just unique to me. Everybody that lived through this. I mean, as I keep saying sometimes to people, HIV affects the person who actually has the infection, but it also infects other it also affects other people, and particularly partners.

**Interviewer:** [00:24:46] Shirleene, you co-authored a book on the Australian journey to marriage equality. Can you talk about how AIDS has impacted that journey for same sex couples?

**Shirleene:** [00:24:57] I think it's an interesting link to talk about. I think obviously at the time of the epidemic and when it was at its zenith, there were real sort of life and death issues to think about, including medication, access to treatment and so on. But I think that what happened during that period did stay in the minds of some people as highlighting a lot of important issues. And, of course, some of those were legal, so you had and I know I'm very aware of cases where this happened, where men were in partnerships with somebody, they would buy a unit together and that perhaps only one person's name would be on the lease. That person would have passed away at during this time period, and the other person would be left with nothing, while the family who might have been hostile towards their son's homosexuality, would take everything. And, you know, there are many cases of this sort of thing happening. And I think by the time the marriage equality campaign started to roll around and really become quite active, which was clearly from about 2004 onwards, although there are certainly cases of people arguing for marriage equality much earlier than that. But by the time that it became sort of mainstream, if you like, that those people who had lived through those experiences or who had seen others go through that experience did emphasize that this sort of thing does matter, that having that legal recognition is really important, and that in our society, marriage is understood to have a particular meaning and that meaning matters when you would like to get access to your partner who may be in a hospital and it matters when you are talking about ownership of properties and things like that. So I think it's a great shame that those men lived through those particular experiences.

And yes, certainly there is a bit of a link that can be drawn there.

**Robert French:** [00:26:30] Relationships recognition was really being talked about 1983/1984, about the time of homosexual law reform in New South Wales, it was partly sparked off by the work of one of the most successful and least known gay community groups, and that was the Gay and Lesbian Immigration Task Force. With the support of the Federal Government, people who had met people overseas or formed relationships were able to bring them in, get them a visa and bring them into Australia. So that's where it starts as an issue.

However, it's emphasised by HIV. So many families copped what I've referred to as the triple whammy: homosexuality, HIV and a husband. It was a shock to many a

family, having to actually realise the true nature of the relationship that their son was involved with. And this actually has a running effect because in the next generation, it's the people who are actually supporting marriage equality. By the time we get to the plebiscite, they knew of gay men, they knew of the relationships within the family. I mean, HIV was the great coming out.

**Shirleene:** [00:27:40] And I guess just to link it back to Queensland, I do, I guess I want to make the point, and I think that is something that we discuss often, that difference in terms of progression, if you like, and recognition. While the southern states are moving more towards recognition and there's a greater federal willingness to talk about overseas partner migration ahead of a lot of places in the world, you do have places like Queensland where men are still being jailed, and publicly named for homosexual activity. Well, up until like 1989 in western Queensland. So, I think that this, when we look at the map of how HIV kind of unfolded in Australia, I really am struck by those regional differences I think.

**Interviewer:** [00:28:17] Are there any last comments that anyone would like to make?

**Nick Cook:** [00:28:21] Well, I'd like to thank Robert while he's here, for what he did. But also all of his peers for what they did. It's just incredible, and not just for the gay community, but for the rest of society.

**Robert French:** [00:28:31] Well, as I've said before, with both HIV and with regard to homosexual law reform, we did what we did because we had to. It was our oppression and we just had to handle it.

**Interviewer:** [00:28:42] On that note, I'd like to thank everyone for listening to this Inner West Library Speaker Series. To enjoy other library podcasts, hop onto the Inner West Library webpage, or borrow from our extensive LGBTIQ collection online and in our libraries. Thank you.