

**LYLE CHAN (b.1967)**

**STRING QUARTET:  
An AIDS Activist's Memoir in Music**

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Total time 1 hour 26 min

**ACACIA QUARTET**

Lisa Stewart and Myee Clohessy, violins  
Stefan Duwe, viola • Anna Martin-Scrase, cello

**I**n the years 1991-1996 I was an AIDS activist. Those years were the height of the epidemic, but also the journey to the crisis' end.

I saw AIDS transformed from a frightening, near-universally fatal illness to what it is today, a chronic manageable condition. This transformation took place within a mere two decades of identifying HIV. In the history of medicine, there had never been progress made at such speed with a disease that was, frankly, so paralyzingly dazzling in its complexity.

This progress came out of an equally unprecedented cooperation, forged initially in hostility and mistrust, between three groups normally wary of each other: the patient community, the medical and pharmaceutical researchers, and the government regulators.

My activism took place as part of three organisations: ACT UP, AIDSX, and the AIDS Council of New South Wales, the last being the organisation that actually employed me in the time I was running drugs from Los Angeles.

During those years, I'd given up music to be an activist. But a composer is always a composer. I did sketch a lot of music. The music were my diaries, a way of writing down feelings. As a composer I think of music as the sound that feelings make.

Some twenty years after these events, I started turning the sketches into performable pieces of music, a process I imagine is the same as when someone turns diary entries into a memoir.

Strictly speaking, the work is not what's called program music, or music that depicts events or a narrative. Every now and there, there is some overt representation (the police whistles, for instance) but mostly it is music that I wrote when I was reflecting on the day's events or even music to comfort myself. The best way to describe the music is to say it's what got written at the time all these things were happening.

And so the memoir is first and foremost the music. The words I've written are a parallel memoir, and the following notes are only brief excerpts from the essays that also function as program notes about the music. The essays are available along with the physical album of the music from [vexations840.com](http://vexations840.com)

## **In September The Light Changes**

My story as an AIDS activist in Sydney began when I was still living in Madison, Wisconsin. My first boyfriend, Geoffrey, whom I met when I was 21 in 1988, was HIV-positive. Mine was the first generation of gay men who never knew a time before AIDS. You had a choice: join the growing grassroots movement against AIDS, or be a bystander, but even as a bystander, you still had AIDS in your face. The radical direct action group ACT UP formed in New York in 1987; I helped found its Madison chapter in 1989. I moved to Sydney in Christmas 1990. I sketched this piece as the new year began, thinking, I travelled thousands of miles, and made new friends in a new city, and they have AIDS too. It really is everywhere. I wrote a music of fluids -- mists and foghorns, half-light and rain. It solidifies to a churning melody, the original tune that Robert Burns had in mind when he wrote one of the greatest poems ever about friends, Auld Lang Syne. Friendships should have the chance to grow old, but maybe not today. Against the tune, bombs fall from the sky, distant explosions heave the landscape and yet the only people who can hear them are those doing the fighting. It's like any war.

### **ACT UP, Parts 1 and 2**

ACT UP, the radical direct action group, was a rag-tag bunch of men and women, mostly in their 20s who used savvy, media-attracting protests to bring attention to the otherwise invisible issues of AIDS – government red-tape holding up treatments access, drug companies who refused to give out drugs they had, housing and employment discrimination against people with AIDS, just to name a few. My training as a molecular biologist made me a natural to work on treatments access, especially translating scientific jargon into everyday language for people with AIDS to understand and helping design clinical trials for new drugs. ACT UP's most famous protest involved invading Parliament House in Canberra with police whistles and orange distress flares to cut the red-tape around drug approval.

Being a core member of ACT UP was exhilarating. One of the earliest protests I participated in involved seizing control of the Federal Health Department's Sydney office. We walked in with flowers, handed them to the receptionists and said politely, please leave. We are taking over communications in the building. Then we answered all calls for the next the next hour, explaining to everyone who phoned all the problems with the federal drug approval system and how there were AIDS drugs available overseas but not here.

In those pre-internet days, the fax machine was the main communication device. We'd organize 'fax zaps', where we'd give out the fax numbers of health ministers and officials and drug companies and ask the community fax

reams of black pages, causing the receiving machines to run out of ink or, even better, jam -- anything to disrupt the 'business as usual' attitude that was killing people with AIDS.

The most visible part of ACT UP's work were these public protests. But the real work was done after the protests won us a seat at the negotiating table. We had to be angry, but we also had to be formidably knowledgeable: we knew which drugs were emerging from the pipeline and we negotiated hard with the medical and pharmaceutical sectors: you give us the drugs, and we give you the data from our bodies that you need to publish your research and get regulatory approval to sell and profit from the drugs.

There's one thing in common across all the music I sketched during my ACT UP days: heightened, intense emotion.

### **Dextran Man, Part 1**

Dextran Man was the underground nickname of my friend Jim Corti in Los Angeles who supplied me with bootleg AIDS drugs that I imported into Australia. Back then the only drug approved to treat AIDS was AZT. It was only limitedly effective. Some people never responded to it, while in others who did respond, the virus quickly became resistant. Everyone's attention was the new drug ddC. Unlike most, it was easy to make. So Jim created various laboratories to manufacture it – a clear violation of the law in so many ways (patent infringement, unauthorised supply of a pharmaceutical, etc.) The several hundred people in Australia who got ddC from me in 1991-92 couldn't know this because I had to protect him, but they have Jim, not me, to thank. As it turned out, ddC was only slightly better than AZT. It extended life, rather than saved it – but for some, this was enough: they were still alive when the protease inhibitors – the first drugs that could be said to save lives – became widely available in 1996.

I thought of Jim as a shaman. The earth was parched and we needed to make rain. The music begins with a rain dance, but when the rain comes, well, there's just so little of it.

### **Mark And Adrian Are Her Sons**

Although I mostly focused on obtaining experimental treatments, I once joined a protest in Parliament House against Member Franca Arena's campaign to give financial compensation to people she called "innocent victims of AIDS" – meaning people with medically acquired HIV – at the exclusion of everyone else, like gay men and other "guilty" victims. The heated confrontation between her and me was captured on Channel 9. Only later did I actually understand her motivations – I discovered Mrs Arena had twin gay sons, whom she loved but hated that they were

gay. Having not just one but both her sons be gay is the “greatest sorrow”, she said. Estranged, the boys fail to attend a family Christmas. She attempted suicide, thwarted by her husband. Her “innocent victims” campaign was her struggle to resolve a powerful conflict – to do something about AIDS, an issue that affected gay men like her sons, yet to maintain the ‘wrongness’ of homosexuality by excluding people like her sons from benefiting. Realising all this, my anger was ambushed by an unexpected feeling: compassion. I still thought what she did was wrong, but I also knew everyone does their best with the mental and emotional resources we have available.

The first two sections of music are extensions of my ACT UP music. The third was written thinking I was glad the Arena twins had each other in the times they didn’t have their mother; the main melody is shared between two indistinguishable violins, like twins who finish each other’s sentences.

### **Dextran Man, Part 2**

Jim Corti was trying to send me ddC even as Los Angeles was engulfed in the Rodney King riots. This was May 1992. He described the wild U-turns he had to make while driving to avoid the knots of violence erupting across the city. And Jim was a white man living in a predominantly black neighborhood. I said, I think it's a good idea if you left town. We'll deal with the ddC when it's over. Even as I said it, I thought, what if it's never over? What if this was Los Angeles from now on, a city permanently seized by racial violence? It was a reminder that for all the problems faced by people with AIDS, there were other crises in the world. The distrust and discrimination at the heart of the riots were the same distrust and discrimination that made AIDS a stigma. No problem is an isolated problem. The music is the sound the chemical molecules made in my head, darting in space, colliding with one another. Dispassionate, elegant, regal, sure of their chemical properties regardless of how humans behaved to each other.

### **Et tu Bruce**

Bruce Brown was the most prominent of ACT UP's activists in Sydney. A gifted organist and harpsichordist, he gave up music to be a full time AIDS activist for the final 4 years of his life. Bruce was a fiery leader, a rousing speech maker, a thorn in the side of everyone who wasn't committed to ending the AIDS crisis. He was one of the frankest people I've ever met. Friends became enemies and vice versa depending on whether you did the right thing by him on the issues that mattered, which were all the AIDS issues. He once explained, "I've spent the majority of my time as an activist basically trying to instil a sense of urgency, not in the “general populace” as they’re called, but in people who work in AIDS. And I find it still isn’t there. I’m running out of new ways to say “urgent”, “critical”, “immediate” and “emergency”. How many ways can you spell “crisis”?” When people were affronted by him, he’d

shrug it off and say, “If we offended you, you needed it.” The title of this musical portrait is from an album by Blossom Dearie, a singer Bruce loved hearing, especially when she sang her campy song ‘Bruce’. I wanted his music to be as elegant and mondaine as I could write it.

## **Night Vigil**

Night Vigil is the final part of Bruce’s story. On several occasions Bruce made it clear to me that if he ever lost his eyesight, it would mean that the balance between quality and quantity of life had tipped over. Every person with advanced AIDS faced this: at what point do you decide that having more life was unacceptable? In late 1993 Bruce was going blind. Only 35, he’d already lived a full life, as an AIDS activist and an early music keyboardist (he co-founded San Francisco’s legendary Philharmonia Baroque Orchestra). It was a calm, lucid decision he made to end it. I was one of three people, all ACT UP activists, he wanted present. Under Australian law, it is a criminal offence to assist a suicide. To be safe, no one could be in the same room. Which was as inhumane a thing as one human being could do to another, to force an already solitary death to be lonely. He took us into his bedroom one at a time to say goodbye. When it was my turn, he took off his watch and said I want you to have this. The law is an ass. I stayed in the room when Bruce swallowed his overdose and fell asleep. We waited through the night, three islands, barely speaking. I remember once someone saying, “I think I’m slowly going mad.” In the morning I touched Bruce, still sitting up in bed, and he was cold. We called the police and medics. One swore because Bruce’s body was difficult to move from rigor mortis. A mere year and a half later, on 25 May 1995, the Northern Territory of Australia became the first place in the world to pass right-to-die legislation. This lasted nine months, then was overturned by Federal Parliament. Today it remains illegal anywhere in Australia to ask for assistance to die. The music is inspired by Bach’s last piece, a organ work by a blind man ready for death, saying to God: before your throne I now appear.

## **After Night Vigil and Dextran Man, Part 3**

I sorted through Bruce's belongings, giving various friends things to remember him by. Most of his belongings were to be sent to his mother in Illinois and to his old harpsichord teacher in San Francisco. While packing his music collection, I found a recording of Richard Strauss’ Four Last Songs. It was the Jessye Norman performance, then 11 years old and already established as a classic. Not that I knew that. I started playing it for no reason. It was the first time I had heard the Four Last Songs and I played it over and over as I packed.

After Bruce's death, many things changed in my life. My boyfriend Colin and I broke up. Jim Corti said I could go live with him in Phuket, where he was spending most of his time, as he was too well-known in Los Angeles to be an

underground drug runner. And he had seen the data from the first human trials of the altogether new type of drug, the protease inhibitors, and he was excited. He told me, "This stuff has the absolute ability, not possibility, to rescue people from the toilet". Jim and I talked about the stuff that we did so that our whole lives weren't only about AIDS. I took classes in musicology at the Sydney Conservatorium; Jim ran a bar. He said, it's comic relief for what else we do.

### **Tony-ony Macaroni, Parts 1 and 2**

These pieces are my tribute to Tony Carden, my fellow activist in ACT UP. He was the most playful of any of us, and had the best sense of humor. He was an actor, had moved from Sydney to New York and was on the brink of a major career but came back to Australia to care for a sick friend. All of ACT UP's demonstrations had a theatrical flair anyway, but Tony brought something only a professional entertainer could. Once, to protest the lack of AIDS beds at St Vincent's Hospital, he led an ACT UP protest that set up a hospital ward, complete with beds, IV drips and nurses on the front lawn of the home of the Health Minister. Tony made me laugh.

His and my outspoken public personas were what people saw. But I wanted to remember his sensitive side, the way he cared for his dog Biche, his surprise gifts and cards to me to sustain our morale, and his extraordinary artwork Warrior Blood. He wasn't a professional artist but it was included in the National Gallery of Australia's exhibition of AIDS-related art in 1994. Warrior Blood was a collection of swatches stained with blood of people he knew, including mine. Tony asked for blood from people he considered soldiers in the war against AIDS. There was HIV+ and HIV- blood on the swatches, and no one was told what was which. My last memory related to him is playing the organ at his funeral, and that shows up in the soaring hymn-like chorale towards the end.

### **Don't Leave Me This Way**

By 1994, AIDS issues had grown too complex to be dealt with by the public protests that were the hallmark of ACT UP. The issues didn't lend themselves to the ingenious sound bites and slogans on placards or t-shirts. The issue was no longer "cut the red tape" or "release the drugs now". We had successfully released all the drugs stuck in the pipeline, only to find these drugs didn't work, not well enough anyway. The pipeline was empty. The solution was for AIDS activists to intervene much earlier in the drug development process, and that task was not suited to the mass-mobilization strategies of ACT UP. So some activists and I started AIDSX which was, on the surface, a treatments information and advocacy organization that published a controversial newsletter, while beneath the

surface, we were a guerilla medical team that ran our own clinical trials using new drugs obtained surreptitiously, such as the new protease inhibitors.

One of our patients was the artist David McDiarmid. David was a celebrated artist in the community because his humane, sexual, colourful paintings formed the basis of one of the most memorable and successful safe-sex education campaigns ever run in the country. And David was possibly the most demanding patient you can imagine. He would refuse to take drugs he considered too toxic, and as a result forced us to come up with new techniques to administer drugs that also benefited other patients. David became an inspiring friend and we cared for him until his death in 1995. I wrote this this long piece thinking about the totality of it -- David's suaveness, sophistication and wit, the resourcefulness, resilience and sheer brilliance of the guerilla medical team.

### **Towards Elysium**

Everyone can point to a year in the 1990s and say, that was the worst year for AIDS, and it would be different for everyone. For me it was 1994. It wasn't that it had any more deaths, I don't think, than the year before or after, but it was the year when many people made decisions to end their lives because there was no point in having more quantity of life when quality of life had become so meagre. And then we (the AIDSX collective) heard about the botched suicides. Euthanasia was such a secretive thing, there was no reliable information on how to do it. So people relied on methods they made up or just heard about. And too many regained consciousness, if you can call it that, from a failed attempt that left the body damaged anyway, just not so damaged as to die. So we, the five core activists at AIDSX, published in our newsletter a recipe using a lethal injection of potassium chloride. Some of us had practised the recipe ourselves so we knew it worked. More so than our use of it, the publication of it was our most radical act, certainly our most blatantly illegal. I regarded everyone who used the recipe a hero. In Greek mythology, Elysium is the special place in the afterlife that the gods reserved for their heroes, especially those who died in battle. I considered everyone who made the decision to end their life to have died in battle. The music that came to me sounds like it had always existed and was just waiting for someone to write it down.

### **Fairy Tale Ending**

By 1996 it became clear that the moment we didn't even dare dream about — though the hope fuelled us everyday -- was here. The new protease inhibitors were not like the other new drugs we trialed over the years — the ones that promised everything in test tube trials but failed in humans. All our patients on protease inhibitors went from death's door to near normal lives. We were calling it the Lazarus effect. The drugs weren't a cure, but they were the



next best thing: something that made you live long enough to be around when a cure came. I wrote this piece as I finally entertained the possibility that I would end my years as an activist and return to my first love, writing music. We got lucky. We got our miracle. We got our fairy tale ending.

And implied in the "happily ever after" of a fairy tale ending is the act of growing old. During the plague years, this was out of reach. Ever since, every time I notice that a friend is older, I feel a secret joy. To see a new gray hair, to see a new crease on a beautiful face. Once upon a time, this was only a dream. This music sounds to me like old World War II holiday songs, where a soldier promises his sweetheart, he'd be home for Christmas. And some of them made it.

– Lyle Chan, 2014

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To the Acacia Quartet. When four men and women with no connection whatsoever to the history of the AIDS crisis resolved to champion a work that was still a jumble of sketches, their faith was the final convincer for me that the work was a story worth telling, even after 20 years. This piece would literally not have been finished without you.

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