

4. ‘Dirty little secret’: Journalism, privacy and the case of Sharleen Spiteri

ABSTRACT

In both the Australian and British debates about media ethics and accountability, a key question about the *News of the World* phone-hacking scandal was whether or not the law should provide stronger protection for individuals from invasion of their privacy by news organisations. There is no explicit reference to privacy in the terms of reference of either Britain’s Leveson or Australia’s Finkelstein inquiries. It can safely be said, however, that invasions of personal privacy by *NOTW* journalists were an important element in the political atmospherics which lead to their establishment. This article also asks where that dividing line should be drawn. However, it approaches the issue of privacy from a rather different perspective, drawing on a case study from relatively recent history involving Sharleen Spiteri, an HIV+ sex worker who caused a national scandal when she appeared on television in Australia in 1989 and revealed that she sometimes had unprotected sex with her clients.

Keywords: accountability, ethics, judicial inquiry, phone-hacking, privacy, public health, public interest, regulations, television

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IN 2011, the *News of the World* phone-hacking affair ignited an international debate about the media and individual rights to privacy. In Britain, Prime Minister David Cameron established a judicial inquiry, chaired by Lord Justice Leveson, to inquire into ‘the culture, practices, and ethics of the press’ (Leveson, 2011). In Australia, the Federal government established an independent media inquiry, led by a former Justice of the Federal Court

of Australia, Ray Finkelstein, QC, to inquire into 'the effectiveness of the current media codes of practice in Australia', and 'any related issues pertaining to the ability of the media to operate according to regulations and codes of practice, and in the public interest' (Conroy, 2011).

In both the UK and Australia, a key question in public debate about the phone-hacking scandal was whether or not the law should provide stronger protection for individuals from invasion of their privacy by the media. There is no explicit reference to privacy in the terms of reference of either the Leveson or Finkelstein inquiries. It can safely be said, however, that invasions of personal privacy by *News of the World* journalists were an important element in the political atmospherics which lead to their establishment.

Debates about the press and privacy are not new. As Karen Sanders points out, in the 1980s and 1990s concern about invasions of privacy was 'the single biggest reason for criticism of British journalists' behaviour by politicians' (Sanders, 2003, p. 77). Privacy has been a crucial issue for the framing of codes of practice and self-regulation for journalists. At stake in many of the ethical dilemmas journalists face is a need to balance individual privacy with public accountability; or as Sanders puts it, to determine. 'Where is the dividing line between the right to freedom of information and that of privacy?' (Sanders, 2003, p. 77)

This article also asks where that dividing line should be drawn. However, it approaches the issue of privacy from a rather different perspective, drawing on a case study from relatively recent history. This case study concerns the story of Sharleen Spiteri, an HIV+ sex worker who caused a national scandal when she appeared on television in Australia in 1989 and revealed that she sometimes had unprotected sex with her clients.

As a result, Spiteri was forcibly detained by the NSW Health Department in a locked AIDS ward, a mental asylum, and a disused nurses' home. After her release she remained under constant surveillance by health authorities for much of the rest of her life, the last four-and-a-half years of which she spent under virtual house arrest in a refuge for homeless drug users in the Sydney suburb of Surry Hills.

Although it created a furore at the time, and had significant and lasting effects on the framing of legislation and public policy on HIV/AIDS, Sharleen Spiteri's story had been largely forgotten by the time she died in 2005. In 2005-10, I and journalism academic and radio documentary producer Eurydice

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Aroney spent six months investigating and researching Spiteri’s story. Our investigation resulted in a 54 min radio documentary, *Shutting Down Sharleen*, broadcast on ABC Radio National’s *Hindsight* programme on March 2010 (Aroney & Morton, 2010).

The documentary raised many questions about the relationship between journalism and individual privacy, and about the balance between the public right to know and the need to protect vulnerable people from intrusive scrutiny by the media. But it also raised a further issue, which has hitherto received little attention in public debate or scholarly discussion. In this article, I argue that the story of Sharleen Spiteri, and our investigation into it, revealed a new and disturbing twist in the privacy debate. Instead of privacy laws being applied to protect individuals, they were being used by bureaucrats in the NSW Department of Health to protect themselves from scrutiny by journalists.

Moreover, Spiteri’s case is not an isolated example. Recent research by Mark Pearson suggests that legal restrictions on the reporting of cases involving forensic mental health patients by journalists also raise important questions about balancing privacy rights and the public’s right to know (Pearson, 2011, p. 97). In another context, the Australian Federal government’s Department of Immigration cites concern for privacy rights as a key reason for denying journalists access to immigration detention centres. This author argues that there is now a broad pattern of government agencies using privacy laws to prevent journalists from raising legitimate questions about the treatment of vulnerable people in their care.

The facts of the case

One Sunday night in July 1989, the national current affairs television programme *60 Minutes* broadcast a report on sex workers and the AIDS epidemic. In the report, a young woman in sunglasses and a blonde wig, given the pseudonym Marianne, is shown wandering the streets of Kings Cross in Sydney. Reporter Jeff McMullen tells the audience in a voice-over that ‘Marianne’ is a sex worker, a drug user and is HIV+. In a face-to-face interview, McMullen asks ‘Marianne’ if she tells her clients that she has AIDS, to which she replies:

I don’t tell them, no, but I make them wear condoms, I mean ... if I told them that I’d probably get killed or something, you know, that’s what I’m worried about. (*Shutting Down Sharleen*, 2010)¹

'Marianne' tells McMullen that she tries to make her clients wear condoms, but that sometimes they won't co-operate; I've caught men trying to take it off when they're halfway there, you know, trying to be shiftily and all that. (*Shutting Down Sharleen*, 2010)

In other words, she sometimes has unsafe sex with them. In his voice-over, McMullen comments:

Marianne says she's been sleeping with at least 10 men a week. It means if only half of them are wearing condoms, at least 1000 men, not to mention their wives and girlfriends, are at risk of getting the AIDS virus. No matter how much we feel sorry for Marianne, she's more dangerous than a serial killer. (*Shutting Down Sharleen*, 2010)

In the days that followed, Marianne's frank admissions to McMullen became front page news in the Sydney newspapers. They created a furor. In an editorial with the headline 'Tough action the only way to fight AIDS,' the *Daily Telegraph* (1989) declared:

If a restaurant persisted in serving poisoned food the Health Department would be right to shut it down. This woman is a public business and must be treated accordingly. (Tough action, *Daily Telegraph*, 2 August 1989)

Marianne's true identity quickly became common knowledge: she was Sharleen Spiteri, a sex worker and injecting drug user who was already well known to health workers and clinics in Kings Cross and Darlinghurst. According to Dr Basil Donovan, then Director of the Sydney Sexual Health Centre, Spiteri's story created 'a public health crisis and a political crisis' (B. Donovan, interview, 27 March 2009).

The NSW state government responded to this crisis by using an obscure section of the *Public Health Act*, previously used to detain tuberculosis patients, to take Spiteri from her home under police guard and forcibly detain her in a closed AIDS ward in Prince Henry Hospital.

Professor John Dwyer was head of the AIDS Unit at Prince Henry Hospital at the time. In the documentary, Dwyer describes the police action as follows:

I remember getting a call to say that the Department of Health wished me to go with one of their senior officers and the police out to Sharleen's place, I think it was about five or six o'clock in the morning, and get her

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and take her out to Prince Henry, which we duly did ... she was very angry and very emotional and it was quite difficult; locked doors and Sharleen kicking and screaming and the like. It was really a horrible situation. (*Shutting Down Sharleen*, 2010)

After some days, Spiteri was released from Prince Henry Hospital, then re-detained in Rozelle Mental Hospital, and then in a disused nurses home at Garrawarra on the southern outskirts of Sydney. All in all, she spent some two months in forcible detention. After her release, Spiteri spent much of the remaining 16 years of her life under constant supervision by officials of the NSW Health Department and carers contracted by NSW Health. In 2001 she was again detained in Foley House, a halfway house for homeless drug users in Surry Hills. She spent nearly five years there under effective house arrest until she was moved to a hospice, where she died in late 2005.

It is important to stress that, when she was first detained in 1989, Sharleen Spiteri had not been charged with any crime, nor had she broken any law that existed at the time. There was no evidence—and none has emerged since—that she had infected a single person with the HIV virus. Indeed, as Basil Donovan states in the documentary, there is ‘not a single documented case of HIV transmission from a sex worker to a client in Australia’s history’ (*Shutting Down Sharleen*, 2010). Donovan, one of the pioneering AIDS physicians in NSW, believed it was wrong to forcibly detain Spiteri:

Detention is an attractive, simple option. But it is a lifetime infection; are you going to lock them up until the day they die? Or do you release them a month later and produce a highly alienated, hostile, disoriented person who is possibly even less in control of their behaviour? Detention is an extremely expensive option and it’s potentially an extreme human rights abuse. (*Shutting Down Sharleen*, 2010)

Spiteri’s story is unique in the history of the AIDS epidemic in Australia. There is a brief account of it in Paul Sendziuk’s excellent monograph *Learning to Trust: Australian Responses to AIDS* (Sendziuk, 2004, pp. 188-92), but otherwise no in-depth journalistic or scholarly account of her case. When we began our investigation, co-producer Eurydice Aroney wanted to discover why Spiteri’s appearance on *60 Minutes* had provoked the policy response it did, with the consequences for the remainder of her life which I have described above. We believed, to use Ettema and Glasser’s phrase, that Spiteri’s

case was a ‘personal story with a public moral’, and one which ought to ‘engage the public’s sense of right and wrong’ (Ettema & Glasser, 1998, pp. 4-5). At the heart of her case, in our view, was a fundamental clash between government’s responsibility to protect the public interest, and the protection of individual liberty under the rule of law.

Secrecy and privacy

As our investigation progressed, we realised that Spiteri’s case also raised important questions about privacy and government secrecy. As Sanders points out, quoting the philosopher Sissela Bok, there is a crucial difference between privacy and secrecy:

A secret is something kept intentionally hidden while privacy is the ‘condition of being protected from unwanted access by others’.
(Sanders, 2003, p. 78)

Spiteri’s story, in fact, was all about secrets; secrets kept by Spiteri herself, by the various health workers, carers and bureaucrats who were involved with her case, and secrets kept by the state. These secrets had an important impact on public policy—some because they were disclosed, others because they were kept hidden. We came to the view that it was not Spiteri’s privacy that the authorities were seeking to protect, but their own secrets.

We were first made aware of Spiteri’s story by Julie Bates. Bates first met Spiteri in 1985, when she was the manager of the Australian Prostitutes Collective and Spiteri was working on the streets of Kings Cross. Later, Bates became closely involved in supporting and caring for Spiteri after she was forcibly detained. An initial interview with Bates provided a wealth of anecdotal information about Sharleen’s life. Bates also believed that Spiteri’s story was ‘a personal story with a public moral’. In her view, Spiteri’s treatment by the health authorities was a clear case of discrimination against sex workers.

Here we have the virus spreading quite substantially in the gay world in Sydney but nobody is being detained here, the law is not being used to lock any gay boys away at this stage. We’ve got this one poor little frightened girl who is typhoid fucking Mary who really needed some social work and some decent caring and looking after her mental health at the time, but she suddenly becomes the whipping girl of HIV in this country. (*Shutting Down Sharleen*, 2010)

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We set out to verify the information provided by Bates, and to gather documentary evidence relating to her case. We recorded some 20 on-the-record interviews with sex workers, AIDS physicians, the former Health Minister Peter Collins, the former Chief Health Officer of NSW Dr Sue Morey, nuns from a religious order which had briefly sheltered Spiteri, health workers, and a number of carers who cared for Spiteri at different times. All had either known her personally or been directly involved in crucial decisions about her case. In other words, they were ‘participatory witnesses’ (Ettema & Glasser, 1998, p. 163). In addition, we conducted some 30 off-the-record research interviews.

From these interviews we learned that a number of individuals who had been directly involved with Spiteri’s case in the late 1980s and 1990s were now senior officials in the NSW Health Department. When we attempted to contact them we were immediately referred to the NSW Health Department Media Unit. This in itself was no surprise; but in response to our enquiries we were told that neither NSW Health nor any of its officials could comment on any aspect of Spiteri’s case, for reasons of patient privacy (NSW Health Media Unit, personal communication, 1 October 2009).

Under the *NSW Health Records and Information Privacy Act (2002)* ‘... personal health information remains covered by privacy principles until 30 years after a person has died’ (*NSW Health Privacy Manual*, 2005, p. 36).

However, as we pointed out to the manager of the NSW Health Media Unit, Jason Donohoe, we were not seeking access to any specific details of Sharleen’s care or case management. Rather, we wanted to discuss with the relevant officials facts and events which were already on the public record. We wanted them to explain the broad policy principles which had guided their decision-making about Spiteri. Donohoe was adamant that the officials to whom we wished to speak could not discuss any aspects of Spiteri’s story with us at all.

There was some irony in this assertion. In fact, the former NSW Health Minister, Peter Collins had disclosed extensive and intimate details of Spiteri’s health records in the NSW Legislative Assembly in 1989. Collins told the Assembly that Spiteri

was addicted to heroin and probably caught AIDS because of needle sharing. She commenced the Rankin Court methadone programme, which she drastically abused: she continued to use heroin, share needles, work as a prostitute without condoms, and she continued to use pills such as Serapax. (Hansard, Legislative Assembly, 1989, 8803)

Collins spoke at length about Spiteri's medical history and her methadone treatment. He said that the Health Department had evidence that Spiteri was 'enticing clients by not using condoms so that she could become pregnant'; that she had undergone a 'surgical procedure'—in the context, plainly an abortion—and that 'she continues to try to become pregnant, with the risk of an AIDS infected baby'.

In other words, the Minister for Health himself had already comprehensively breached Spiteri's privacy. Technically, of course, the *NSW Health Records and Information Privacy Act (2002)* had not been in force when he did so; but concerns about the breach of confidentiality were raised in Parliament at the time by the Shadow Health Minister, Dr Andrew Refshauge. Peter Collins replied that

[w]e are not talking about somebody's private medical records; we are talking about somebody... who went on a national television programme and said that she had AIDS, she knew she had AIDS, she did not use condoms and she was quite unconcerned about the number of clients that she took on, knowing that she could infect them with AIDS.
(Hansard , Legislative Assembly, 1989, 8805)

Interestingly enough, Peter Collins' justification for revealing these intimate details of Spiteri's medical history parallels a justification often used by journalists for breaching personal privacy. Sanders characterises this as the 'self-immolation argument'. In this view, individuals who deliberately reveal personal information in the media are invading their own privacy: 'by placing much of their personal lives on the record, they cannot complain when the media delves deeper' (Sanders, 2004, p. 86). As Sanders says, this argument is most often applied to celebrities and others who *choose* to be in the public eye.

There can be little doubt that what Sharleen did when she chose to be interviewed by *60 Minutes* amounted to 'self-immolation'. Prior to that interview, however, she was not a celebrity; she was, to use a phrase adopted by Sanders, an ordinary person 'unexpectedly thrust into the public eye' (Sanders, 2003, p. 85).² The crucial question is whether or not Sharleen was able to make an informed choice to invade her own privacy.

This question is very difficult to answer. In the course of our investigation, we interviewed Ron Hicks, the journalist who was responsible for bringing

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her story to the attention of *60 Minutes*. Hicks was a medical writer who had worked for *The Australian* newspaper and written extensively about the AIDS epidemic during the 1980s. At the time he met Spiteri, Hicks was working on a story about the ‘second wave’ of the epidemic; the possibility that it might spread into the heterosexual population. Hicks described how he first met Spiteri:

The main target at that time, we were looking at the intravenous drug community. . . . I wasn’t looking for a prostitute with AIDS. So I went to a doctor in Kings Cross, and he put me onto someone in the community health field, and they in turn put me onto Sharleen, and that just blew my mind. (*Shutting Down Sharleen*, 2010)

Hicks (1989) published a profile of Spiteri (under the pseudonym Marianne) in *The Australian Magazine*. In the published story, Spiteri had told Hicks that she always made her clients use condoms. Soon afterwards, Hicks met Spiteri for a cup of coffee. During their conversation, Spiteri revealed that, contrary to what she had told him before, she sometimes had unprotected sex with clients: ‘She revealed to me that people paid her more money to have sex without a condom’. (*Shutting Down Sharleen*, 2010). After this off-the-record conversation, Hicks approached producers at *60 Minutes* to see if they would be interested in pursuing her story on their television programme. In our interview with Hicks, he argued strongly that he believed at the time he was acting in the public interest:

To me it was a major story. I’d been in the health field for a long time and you could see AIDS was going to be a major problem, and a major major problem if it got into the general community. For a long time people thought it was just a disease for the gay community—and it sounds brutal—but many people didn’t care that much. But here was a living breathing example that it had crossed over and it was going to potentially hit a lot of people. (R. Hicks, interview, 4 November 2009)

Hicks believed he was ‘raising awareness of a potential catastrophe’. He effectively acted as a broker between Sharleen and *60 Minutes*. Spiteri agreed to be interviewed on camera, on condition that *60 Minutes* fly her to South Australia to visit her mother and her son. Two years previously, Spiteri’s mother had fought and won a custody battle to have the son, then an infant,

removed from Spiteri’s care and placed in the care of the mother. Hicks told us that Spiteri ‘consented all the way’ to the interview because she wanted to see her son (R. Hicks, interview, 4 November 2009). When the *60 Minutes* programme was finally broadcast, however, Spiteri became extremely distressed. As mentioned above, the reporter Jeff McMullen had told the audience in a voice-over that Spiteri was ‘more dangerous than a serial killer’. We asked Hicks whether he thought that was appropriate:

Yes, the interview was pretty brutal. It had to be, I think, to get to the truth of the matter, and yes, it would have been very difficult for Sharleen. But she knew what she was getting in for. (*Shutting Down Sharleen*, 2010)

Hicks’ last words—‘she knew what she was getting in for’—clearly underline his view that Sharleen had made an informed choice when she gave her consent to be interviewed by *60 Minutes*. Certainly, after her initial distress when the *60 Minutes* program went to air, Sharleen did not shy away from contacts with the media. While she was forcibly detained at Prince Henry, a television news team landed a helicopter in the grounds. Sharleen managed to elude her guards and get outside for long enough to give them an on-the-spot interview, in which she declared

I’m going through a bit of a hell and trouble here because they won’t let me go out, they won’t let me go for a walk. I’m getting trapped in here actually, it’s like a prison. (*Shutting Down Sharleen*, 2010)

Julie Bates, who became involved with Spiteri’s care when she was released from Prince Henry, saw these contacts with the media as part of a pattern of behaviour:

She was seeking attention, as a lot of young people who have been mistreated do, and her attention-seeking ultimately got her into a lot of difficulties (J. Bates, interview, 7 April 2009).

Her forcible detention at the hands of NSW Health Department had only added to her notoriety:

Sharleen had found the ultimate attention... I just kept saying to her, don’t do it Sharleen, you’re just making life a whole lot more difficult

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for yourself. Keep away from them. They’re damaging you, they might be giving you money, but they’re making your life really miserable. (Bates, interview, 7 April 2009).

Spiteri’s willingness to continue speaking to the media after the *60 Minutes* report could be construed as further evidence of ‘self-immolation’. But did this mean she had forfeited her right to privacy? This was the argument NSW Health Minister Peter Collins had used to justify making her confidential health records public.

Precisely this question—as to whether or not individuals may voluntarily relinquish their rights to privacy—is at the heart of a series of legal and philosophical arguments explored by Anita Allen in her recently published book *Unpopular Privacy: What Must We Hide?* (2011). A distinguished scholar of legal philosophy, Allen argues that there are certain kinds of privacy provisions in law which may be unpopular with those they are intended to benefit. One of the key questions she raises is whether individuals should always have a right voluntarily to waive their privacy rights, and if so, why:

Individuals in the United States commonly waive the physical and informational privacy rights they possess under the law. Could certain privacies be so important that they should be legally protected and the legal protections not subject to voluntary waiver by their intended beneficiaries? (Allen, 2011, p. 7)

Physical privacies relate to the human body, while informational privacies may range from professional obligations to confidentiality (for example, of doctor to patient), to information about our health, or our intimate relationships, that we as individuals choose to keep private. Allen notes that the major federal health law in the United States, the *Health Insurance Portability and Accountability Act* (HIPAA) imposes confidentiality on healthcare providers—doctors, hospitals, health funds—but does not require *patients* to protect their own privacy.

Allen argues that privacy laws need to go further. She believes there are certain kinds of privacy which embody public—and private—goods so important that they must be enforced by governments, even against the wishes of those they are intended to protect:

I believe it can be legitimate for liberal, egalitarian governments to mandate physical and informational privacy even when the privacy in

question is unpopular—unwanted, resented, not preferred, or despised by intended beneficiaries or targets... When people abandon privacies typically needed for self-respect, reputation, confidential relationships and other forms of flourishing, it is time to consider mandating the privacy that is unwanted or to which people have become indifferent. (Allen, 2011, pp. 9-10)

Allen’s argument raises some important questions for the practice of investigative journalism. In Spiteri’s case, it could be seen as a strong endorsement of the NSW Health Department’s insistence that they could not discuss her case with us; in this view, even though Spiteri was ‘indifferent’ to her own privacy, NSW Health, as a government agency which had a duty of care to her, ought not to be.

Whether or not this remains a valid argument after the person is dead is another question. But Allen is also acutely aware that, under some circumstances, privacy can be used by governments for reasons which have little to do with individual flourishing:

Government can turn privacy into a weapon against its own citizens and charges. Government can coerce privacy to reduce the transparency of its operations and the accountability of officials. (Allen, 2011, p. 23)

To adopt Allen’s criteria, we had to ask ourselves as journalists whether NSW Health was truly seeking, on Spiteri’s behalf, to protect privacies needed for ‘self-respect, reputation, confidential relationships and other forms of flourishing’, or whether it was acting to ‘reduce the transparency of its operations’. We believed, on the basis of the evidence we had been able to gather, that the latter was the case.

The most expensive public patient

After two months in forcible detention in 1989, Spiteri was released. However, multiple sources whom we interviewed for our documentary stated that Spiteri spent most of the rest of her life under constant surveillance and supervision by the health authorities, neither a prisoner, nor a free woman.

One of those sources was Professor Julian Gold, director of the Albion St Centre in Sydney, which provides medical services to people with HIV. Spiteri had had contact with the Centre before her period of detention, and after her

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release she became one of Professor Gold’s patients. Gold told us that the NSW government believed Spiteri needed to be supervised around the clock:

One of the responses of the government, understandably, was, well, if Sharleen can’t be trusted not to spread HIV, then it would be necessary to have somebody with her at all times accompanying her. And NSW Health assigned a team of healthcare workers to be with her 24 hours a day, seven days a week. (*Shutting Down Sharleen*, 2010)

As a consequence, according to Gold, she became ‘the most expensive public patient in the history of NSW Health’ (*Shutting Down Sharleen*, 2010).

It could be argued that Spiteri actually benefitted from the constant attention of the authorities. Professor John Dwyer, who had been tasked with accompanying the police when Spiteri was first detained, continued to be involved with her care for two years after her release:

I remember when the department arranged for her to get an apartment, going out frequently in the first few weeks to the apartment and people were buying her food, bringing her methadone. She had some wonderful people trying to support her and the Department of Health mobilised the most amazing amount of resources to help this one person and to try and keep her out of the public eye and behaving herself. (J. Dwyer, interview, 2 November 2009)

Dwyer’s words are significant; Spiteri was receiving a very high level of support and care, but this was also intended to keep her ‘out of the public eye’.

Both the state and the Federal government had committed themselves to a policy of working with affected communities, such as the gay community, injecting drug users, and sex workers, rather than criminalising them. This approach is now seen as the ‘gold standard’ in AIDS policy, a courageous and co-ordinated policy response (Malek, 2006) which is now ‘globally recognised as a success’ and which kept rates of HIV infection among the lowest in the world (AFAO, 2010).

The policy depended on an unusual level of bipartisan political support in state and federal parliaments. It required political courage on the part of politicians and a willingness to lead community attitudes. According to Ingrid van Beek, director of the Kirketon Road Centre, one of the longest-established AIDS services in NSW, ‘for the whole of the HIV programme to continue to

be able to operate required the community to be generally and broadly supportive’ (*Shutting Down Sharleen*, 2010). The public outcry after Spiteri’s appearance on *60 Minutes* suggested that that community support was fragile. Thus it could be argued that keeping Spiteri ‘out of the public eye’ and under constant surveillance not only protected her privacy, but bolstered support for a vital and highly sensitive public health policy.

The crucial question here is whether or not, in so doing, the NSW Health Department deprived Spiteri of the normal civil liberties which any other individual could expect to enjoy under the law.

The ‘Very Naughty Persons Committee’

After Sharleen was released from detention in 1989, the then Director of the NSW AIDS Bureau, Ruth Cotton, became directly involved in managing her case. According to Dr Basil Donovan, then director of the Sydney Sexual Health Centre, Cotton was convinced that forcible detention should be a last resort; she believed that ‘there were obviously more humane sensible steps you could take before you got to that point’ (B. Donovan, interview, 27 March 2009).

Cotton set up a committee of health professionals, bureaucrats and community representatives to look at alternatives to detention. Its full name was the *Assessment Panel for People who Knowingly Expose People to HIV without Informing Them*, but it quickly became known among its members as the ‘Very Naughty Persons Committee’ (Donovan, interview, 27 March 2009). Basil Donovan, a pioneer in AIDS medicine in NSW, was the permanent convenor of the committee. According to Donovan

[t]he overwhelming principle was for the Health Department not to become seen as draconian germ police—we wanted to work with the community rather than against the community. (Ibid.)

The committee developed a five-step protocol for dealing with people with HIV/AIDS who knowingly placed others at risk of infection. The first three stages involved counselling, interventions by relevant community organisations, and the issuing of a letter of warning from the Chief Health Officer or Secretary of Health (NSW Health Guidelines, 1990, p. 6).

Only if these approaches were ineffective did the guidelines recommend proceeding to the fourth and fifth stages, which involved ‘placing restrictions

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on a person’s living circumstances, activities and employment’ and, if this failed, ‘detention in a hospital or quarantine unit or other appropriate place as a last resort’ (p. 7).

At both these stages, the guidelines stated that a court order would need to be obtained by the health authorities, and that the order should be given for a fixed time period, subject to appeal and review by a magistrate. In other words, the clear intention of the guidelines was that there be a process of public scrutiny of any such orders.

Yet, when we applied to NSW Health for details of these orders, we were told again that releasing them would breach Spiteri’s privacy.

Most reasonable people would regard living under constant surveillance, as Spiteri did for more than 15 years, as a ‘restriction on a person’s living circumstances’. It appears, then, that for all that time, Spiteri was living in a kind of bureaucratic no-man’s-land, a state of legal limbo. This would have far-reaching consequences for the final years of her life.

From suburban detention to house arrest

In 1997, the NSW Health Department moved Spiteri from the inner city to a house in Canada Bay, a quiet Sydney suburb. According to Mark Johnson, one of her carers at the time, Spiteri was ‘very fond’ of the house; compared with the innercity flats she had been used to, it was ‘a really cosy home... a brick veneer bungalow with three bedrooms, a kitchen and back yard’ (M. Johnson, interview, 9 December 2009).

Nevertheless, Johnson described Spiteri’s circumstances at Canada Bay as ‘suburban detention’. Johnson was adamant that she was subject to a public health order of some kind for the entire time she was living there. The order required her written consent, and he saw Spiteri sign it. Johnson says she was aware that, if she refused to sign the order, the regime of 24-hour supervision would end:

She knew she couldn’t be held, she could just leave Canada Bay. She would speculate quite freely about being out of care, having her freedom. (Johnson, interview, 9 December 2009)

In the end, however, Spiteri always signed the orders.

Once again, it must be stressed that the issues raised by Spiteri’s situation are very complex. It could reasonably be argued that, in signing the order she

gave her informed consent to remaining in 'suburban detention'. Yet Johnson also told us that Spiteri was aware that, if she left her home at Canada Bay, she would be more exposed to the influence of her father; and he, as we discovered, was not a benign influence in Spiteri's life.

Spiteri's father was her only regular visitor at Canada Bay. According to Mark Johnson, her father exercised 'complete control' over her. She regularly gave him money from her disability pension; but in the final year of her stay at Canada Bay she began to turn to other sources of income. By this time, Spiteri was spending some nights alone, as NSW Health had withdrawn part of the funding for her 24-hour supervision due to budget constraints. Johnson and another of Spiteri's carers, Nadine Ballantyne, became aware that Spiteri was engaging in sex work, and giving the proceeds to her father. Ballantyne told us that Spiteri would 'go without to give him money', and began to do sex work 'to get a bit more money, often to give to her dad' (*Shutting Down Sharleen*, 2010).

Johnson and Ballantyne reported to their supervisors that Spiteri was engaging in sex work. One of them was Ross Johnston, a mid-level NSW Health official who administered the funding for Spiteri's care. Johnston told us that the situation at Canada Bay was 'a powder keg waiting to blow':

It was reported to me that Sharleen's father was in fact her pimp, and he took exception to the staff seeking to stop Sharleen from working as a prostitute. (*Shutting Down Sharleen*, 2010)

It should be stated here that we approached Spiteri's father on a number of occasions asking him to respond to these allegations, but he refused to be interviewed unless he was paid. Payment for interviews is prohibited by ABC Editorial Policies.

Ross Johnston referred the reports concerning Spiteri's father upwards to senior management at NSW Health; specifically, to the AIDS Bureau of NSW Health, which had ultimate responsibility for her case. But despite what Johnston describes as the AIDS Bureau's 'keen interest' in Spiteri's case, the reports were ignored. Spiteri's carers became increasingly desperate and threatened to go on strike. The situation finally came to a head when some of Spiteri's neighbours threatened to hold a public meeting and invite the media. At this point, NSW Health took decisive action. Spiteri was transferred to Foley House in inner city Surry Hills.

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Foley House was a refuge for drug users with HIV who were homeless and considered to be ‘at risk’. Normally, it was intended to provide temporary respite accommodation for periods of up to three months. Spiteri spent nearly four and a half years at Foley House, under effective house arrest. According to Mark Johnson, who continued to care for her there, she could only leave the premises accompanied by two carers:

Sharleen never went anywhere alone, never, anywhere. It was a locked, secure residence. It had a grille on the door and the workers had to let you out. (M. Johnson, interview, 9 December 2009)

In the final months of Spiteri’s stay at Foley House she became increasingly ill, and was transferred to a hospice, where she died in late 2005. According to Julie Bates, who visited her shortly before her death, the final public health order was taped to the wall above her bed.

Unanswered questions

As I have indicated above, we believed as journalists that it was important to understand how NSW Health had made decisions about Spiteri’s care at Canada Bay, and her transfer to Foley House, and to determine whether or not there had been any independent scrutiny of those decisions. We applied under Freedom of Information for all the public health orders relating to Spiteri’s case. We obtained access to a total of seven orders—five made in 1989, which covered her initial period of forcible detention, and two made in 2001, which required her to refrain from sex work and ordered that she be ‘detained under appropriate supervision at the premises of Foley House’ (Public Health Order, 2 April 2001).³

In between these two sequences of orders, there was a period of 12 years from 1989 to 2001 for which no public health orders were provided. So what were the orders which Spiteri had signed every year—and what was their legal status?

In February 2010, after more than four months of requests to the NSW Health Media Unit, we were granted an interview with the current chief Health Officer, Dr Kerry Chant. Dr Chant herself had no direct knowledge of Spiteri’s case, but we were told that she was the only officer of NSW Health who could speak publicly on the matter. We provided questions in writing before the interview. In one question, we asked Dr Chant to confirm that

Spiteri was *not* under a Public Health Order between 1989 and 2001. Dr Chant's answer was as follows:

We've provided all the relevant public health orders, so there would have been a period where we had work with Sharleen and suggested a number of management strategies for Sharleen and they would have been offered to her and her acceptance of those would have given us an assurance that we'd achieved that balance between risk to the community and her individual needs. (K. Chant, interview, 16 February 2010).

In a subsequent email the head of the NSW Health Media Unit, Jason Donohoe, stated that:

Intensive supervision outside the framework of a Public Health Order is provided with the consent of the client concerned. Providing more detail would involve release of personal health information of Ms Spiteri and release could be contrary to new privacy laws. (J. Donohoe, personal communication, 18 February 2010)

It was clear that our investigation had finally hit a brick wall. We believed that, as journalists, we had taken all possible steps to obtain the information which would enable us to provide a fair and balanced account of what had happened to Spiteri, and why it had happened. Our documentary was broadcast shortly afterwards. We believe it left important questions unanswered by NSW Health. But was there any more to know? Could the health authorities have dealt any differently with what was clearly a very complex case, involving an individual who was extremely difficult to manage? Could Spiteri's story have had a different ending?

Privacy and human flourishing

One possible answer to these questions relates to the events in the final months of Spiteri's 'suburban detention' at Canada Bay. Timely action to make Sharleen Spiteri—and her father—aware of the consequences of her engaging in sex work might have obviated what NSW Health later decided, under threat of renewed media attention, was the necessity to take her from the house at Canada Bay, where was apparently happy, and place her under house arrest. Although Spiteri did finally receive assistance from Legal Aid when the order to detain her at Foley House came before the Administrative

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Appeals Tribunal (AAT), it appears that there was no one to advocate for her prior to that, or to assist her in her decision-making. As Dennis, a resident at Foley House who knew Spiteri, described her story, ‘she was the state’s dirty little secret, and she disappeared below the radar’.

Whether such independent scrutiny or advocacy might have led to Spiteri spending the final years of her life in more humane and dignified circumstances can, of course, only be a matter of speculation. There are, however, some parallels in recent research by Professor Mark Pearson on the reporting of forensic mental health cases which suggest that more openness can lead to better outcomes for individuals and greater public accountability.

Pearson defines forensic patients as those

whose health condition has led them to commit, or be suspected of, a ‘criminal offence’ (AIHW, 2010, p. 140) or as those who were unfit for trial or of unsound mind when they committed an offence (*Mental Health Act 2000* (Qld), Schedule 2)—and those who were not facing a criminal trial but were facing the issue or review of ‘compulsory treatment orders’ by mental health tribunals or their equivalent bodies (Pearson, 2011, p. 93).

It should be clear already that there is a *prima facie* similarity between the situation of forensic patients who are subject to ‘compulsory treatment orders’, and Spiteri’s situation when she was under the care and supervision of NSW Health.

Typically, the kinds of forensic cases which Pearson’s research covered are subject to review by Mental Health Tribunals or similar bodies. Journalists wishing to report on their proceedings must comply with ‘stringent non-publication, non-identification, and secrecy provisions’ if they want to report these cases; and if they identify the individuals concerned, they may face ‘substantial fines or jail terms’ (Pearson, 2011, p. 96).

What this means in practice is that people who are involuntary patients held in secure facilities in mental hospitals, or the forensic wards of prisons, can effectively become non-persons. Unlike prisoners in the criminal justice system, they cannot be named by journalists; and while prisoners in the criminal justice system can have their appeals and applications for parole heard in open court, the cases of forensic patients before mental health tribunals are effectively closed to the public and exempt from scrutiny by the media.

As Pearson points out, across all the jurisdictions he reviewed, the law seeks to strike a balance between the right to privacy of forensic patients, and ‘the public interest in open, transparent and accountable proceedings’. In his view, however, there is a further important principle which needs to be considered; one which, it could be argued, is fundamental to the rule of law:

Of course, it is not just a case of the patient’s privacy rights versus the public’s right to know. Patients also have the important issue of their liberty at stake in such proceedings, which might well be compromised by a secret, unreportable tribunal or court process. (Pearson, 2011, p. 96)

Spiteri’s ‘suburban detention’ while in the care of NSW Health, and the orders which were used to restrict her behaviour, are comparable to a ‘secret, unreportable tribunal or court process’. To paraphrase Pearson, NSW Health certainly did its best to make those circumstances and orders secret and unreportable; and the important issue of Spiteri’s liberty was unquestionably at stake.

The aspects of the mental health and criminal justice system reviewed by Pearson are not the only example of the use of privacy laws to restrict reporting by journalists. In Australia, successive Federal governments have routinely used privacy provisions to deny journalists access to immigration detention centres, on the grounds that to do so would create a ‘breach of residents’ reasonable expectation of privacy’ (MEAA, 2011, pp. 4-5).

Plainly, there are important and sensitive issues which need to be considered by journalists when they report the cases of people in immigration detention. But the Department refuses to allow journalists to interview detainees even when those detainees have explicitly given their consent. One senior and highly respected Australian journalist has argued that the Department of Immigration’s motivation has little to do with concern for detainees’ privacy. In an article in *The Australian* newspaper in January 2012, Mark Colvin, presenter of the daily radio current affairs programme *PM*, gave this blunt assessment of the Department’s media policies:

The first principle of journalism is you don’t write stories about issues, but about people, and they are trying to stop us from doing that. (*The Australian*, 9 January 2012)

In all three instances—Spiteri’s story, the reporting of forensic mental cases,

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and journalists’ access to detention centres—it can be asked whether privacy provisions operate to protect the rights of vulnerable individuals, or to protect government and its agencies from public scrutiny. As Sanders writes:

Privacy is precious, but if we use it to shield actions which undermine the common good, then the purpose of privacy itself—to allow the human being to flourish—is not served. (Sanders, 2003, p. 91)

Did the secrecy which surrounded Sharleen Spiteri allow her to flourish? Did it protect ‘self-respect, reputation, confidential relationships’, the criteria which Anita Allen identifies for mandating privacy? All the evidence suggests that the opposite was true; that, to quote Spiteri’s friend Dennis once again, NSW Health sought to use privacy laws as a way to conceal its ‘dirty little secret, and in so doing, ‘to reduce the transparency of its operations and the accountability of officials’ (Allen, 2011, p. 23). In Spiteri’s case, there was no-one to ‘guard the guardians’.

Notes

1. All references to the original *Sixty Minutes* programme (broadcast Sunday, 23 July 23 1989), are to excerpts from the programme broadcast in the radio documentary *Shutting Down Sharleen* (Aroney/Morton, 2010).
2. The phrase is adapted from Belsen (1992) and Kieran (1998).
3. We were also given access to nine decisions of the NSW Administrative Appeals Tribunal (AAT), which reviewed and extended the original order to detain Sharleen Spiteri at Foley House.

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