[issues]

# AN UNFORTUNATE HISTORY

Twenty-two years ago, an exposé in this magazine damned a controversial cancer experiment at National Women's Hospital. Now a new history argues *Metro* and the subsequent official inquiry got it wrong. Sandra Coney, one of the authors of the original article, finds serious flaws in the latest revisionist arguments.

t is 22 years since the Cartwright Report was released, with its devastating critique of the "unfortunate experiment" at Auckland's National Women's Hospital. For most of us who were involved, it is long ago. We have all grown older and many of the patients and the chief protagonists have died in the intervening years.

Anyone under the age of 30 or even 40 could wonder what the new revisionist history by Linda Bryder is about. Her claims may seem plausible to people who didn't live through the day-by-day media coverage as events unfolded over 1987 and 1988.

Bryder's claims burst into view with a shock-horror *Listener* cover: "Cancer Scandal", "The Truth about the 'Unfortunate Experiment'", "Exclusive: How Sandra Coney, Phillida Bunkle and the Cartwright Inquiry into a doctor's methods got it WRONG". The hagiographic lead article quoted no one but Bryder. Putting aside the normal convention of balance, the *Listener* had accepted the condition of Bryder's publisher, Auckland University Press, that the book was embargoed. Unfairly, no one else could see the book until almost a week after the *Listener* came out. Radio NZ also gave Bryder a platform, although it subsequently interviewed a medical adviser to the inquiry, Dr Charlotte Paul.

The Listener has continued in this vein. Each article on the topic and even some letters have been accompanied by a rebuttal from Bryder like a one-woman Greek chorus. Looking through the Listener archive, I can find no other instance where the magazine has allowed a person interviewed to dominate the debate in this way. So it is important to begin critiquing the critiquer, but first, some context is important.

PHOTOGRAPHS BY STUART BROUGHTON AND GIL HANLY.

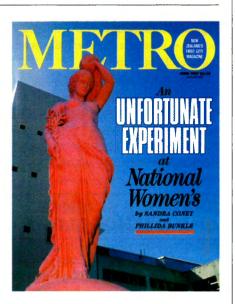


SANDRA CONEY

## THE "UNFORTUNATE EXPERIMENT" AND THE CARTWRIGHT INQUIRY

The Cartwright Report followed a lengthy committee of inquiry, led by Judge (now Dame) Silvia Cartwright. The inquiry was set up following an article written by Phillida Bunkle and myself, published in this magazine in June 1987.

Metro's headline, An Unfortunate Experiment at National Women's, was the description given by Professor (now Sir) David Skegg, the current vice-chancellor at Otago University. Dr Herbert Green



METRO, JUNE 1987

had tested his theory that carcinoma in situ (CIS) was not a precursor of invasive cervical cancer by "following" women with CIS without eliminating the disease.

We based our story on the case of Clare Matheson, called "Ruth" in the *Metro* story. Over a 15-year period, Matheson was recalled to the hospital clinic 44 times, underwent 28 cervical smear tests, five biopsies, four operations with general anaesthetic and 10 colposcopic examinations (magnifying the cervix).

In 1979, Green discharged her despite a pathology report showing she still had CIS.

Six years later, invasive cervical cancer was diagnosed by another gynaecologist and she had radical treatment with



surgery and radioactive rods.

As more and more patients developed cancer, Green was confronted by two of his colleagues, Dr Bill McIndoe, who was operating the colposcope, and Dr Jock McLean, the head pathologist. In 1973, both these doctors appealed to the hospital and board management to stop the trial but, although Green stopped recruiting new patients, the matter was glossed over. Many of Green's patients still had uncured disease when he retired in 1982.

Finally, in 1984, McIndoe, McLean, Dr Ron Jones and a statistician published a medical paper ("the 1984 paper") which looked at the outcome for women managed under this regime. They found that only 1.5 per cent of women whose smears were normal after treatment developed cancer, while 22 per cent of those "followed" with abnormal smears developed cancer.

Judge Cartwright's report essentially confirmed this story, but she went back to basics to arrive at her conclusions. She heard from 59 witnesses, including a number of international experts in cervical cancer. A further 77 witnesses, mostly patients, were heard in private. Nearly 1200 patient files were examined by her medical advisers.

There were a number of attacks on the inquiry findings, most prompted by particular National Women's doctors, and by Valerie Smith, a neighbour and prime defender of Green. Smith and Dr Bruce Faris initiated a High Court review of the report, but this was struck out by consent. Smith's claims and those of Dr Graeme Overton formed the basis of Jan Corbett's debunking Second Thoughts on the Unfortunate Experiment published in this magazine in mid-1990.

For two years after the inquiry, it was regularly in the news, but the challenges seemed answered in October 1990 when Green's superior, Professor Dennis Bonham, was found guilty of disgraceful conduct by the Medical Council for his part in the National Women's affair (Green was not charged as he was too ill). This followed an extensive hearing involving local and overseas medical experts and ethicists, which basically examined the matter anew.

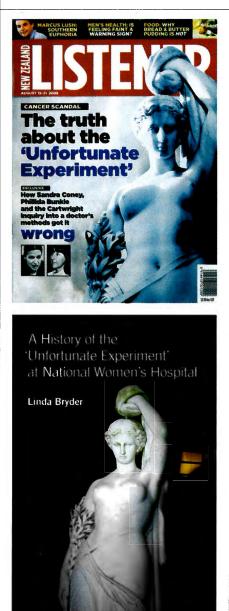
At this stage, it appeared the truth had been well established and the arguments laid to rest.

#### BRYDER REVISES HISTORY

In 2003, Dr Linda Bryder, of Auckland

University's history department, gained a grant from the publicly resourced Marsden Fund, which operates under the auspices of the Royal Society of New Zealand. She was awarded \$345,000 over three years, one of the larger grants in the social sciences area. Her project

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was entitled Women and health in New Zealand 1945-2000, with special emphasis on National Women's Hospital.

Bryder's recent A History of the "Unfortunate Experiment" at National Women's Hospital essentially re-rehearses Corbett's 1990 arguments. It is an extreme denial of the Cartwright findings. According to Bryder, Green was not conducting an experiment, he was applying best practice, then writing up the results. He was doing only what others in other parts of the world were doing, and he met contemporary international standards for management of CIS and research ethics.

Women were fortunate to be in his care and they came to no harm. If women at the hospital got cancer, it was only at the expected rate, and cases where cancer developed could not be put down to his management.

Other practices at the hospital that alarmed the public — such as teaching vaginal examinations on anaesthetised women — were part and parcel of attending a teaching hospital.

As feminists, Phillida Bunkle and I should have supported Green, because feminists favoured less-interventionist approaches in medicine. However, we put this aside in pursuit of our larger goal of "bringing to heel a patriarchal medical institution".

# BRYDER'S SCIENCE AND METHODOLOGY

On a superficial reading, the book appears scholarly and is littered with references and detail. If you were not familiar with the chronology of the period, and with the medical areas under discussion, you could be convinced. Lay readers could also be quite impressed by the Marsden Fund backing, the University of Auckland imprimatur, the publication by the Auckland University Press and Bryder's title of professor (she was granted a personal chair in June this year).

But a closer examination reveals a number of fundamental flaws.

Bryder has got some major scientific arguments at the heart of the inquiry seriously wrong (her significant medical errors have been described by Dr Charlotte Paul and Professor Linda Holloway, two of the medical advisers to the inquiry, in the *Listener* of September 12) and her methodology is based on selective and incomplete use of sources — such that she often distorts the intent of original statements — muddled chronology, and tenuous arguments. On some critical matters, she uses suspect sources (such as newspaper correspondence and reports and diatribes from defenders of Green like Smith) as accurate, rather than going back to primary sources. Uncomfortable facts that don't support her theories are simply omitted. I will give examples of these.

THIS IS AN EXTRAORDINARY OMISSION... THIS IS RECENT, NOT DISTANT, HISTORY AND MANY OF US ARE STILL ALIVE.

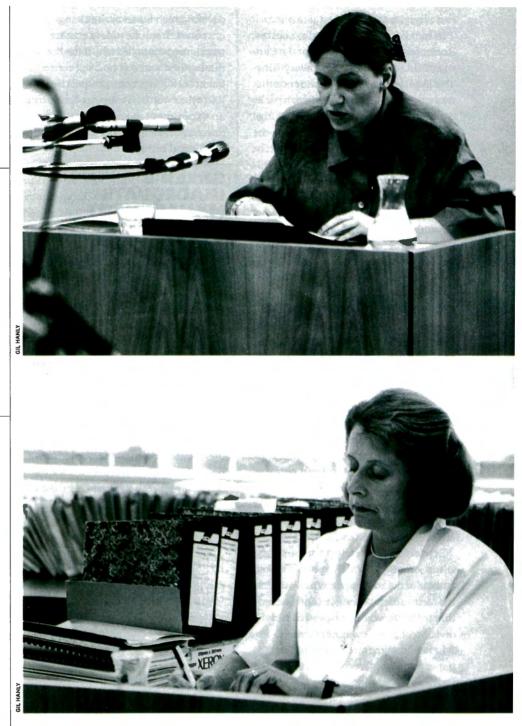
Importantly, she has not interviewed any of the medical advisers, counsel or other personnel from the inquiry, none of the parties who "prosecuted" the case against the hospital, none of the women concerned, and critically, since she singles me out for particular attack, she did not interview me, or my co-author Phillida Bunkle. Neither did she specifically interview Dr Ron Jones, the one surviving National Women's doctor who wrote the 1984 paper. Had she done so, she would not have been so muddled in her depiction of that document.

In a recent *Listener*, Bryder said, "I interviewed none of the participants in the inquiry." This is technically correct, but not the whole story.

Bryder contracted a researcher, Dr Jenny Carlyon, to conduct interviews of more than 90 people, mostly from National Women's, as part of the Marsden grant project. Bryder uses a number of them in her book to defend the activities of Dr Green.

This means that while current and former hospital staff, including archdefenders of Green, were given the chance to express a view, others involved in the inquiry and its follow-up, but not connected to National Women's, were not.

This is an extraordinary omission. After all, this is recent, not distant, history and many of us are still alive. Consequently the book lacks balance and is unfair.



TOP: SANDRA CONEY GIVING EVIDENCE AT THE CARTWRIGHT INQUIRY. ABOVE: SILVIA CARTWRIGHT AT HER DESK, WITH PATIENTS' FILES IN BROWN BAGS LINED UP BEHIND HER.

Bryder has even sought out written records owned by selected individuals who were deeply unhappy about the inquiry, such as Dr David Cole, dean of the medical school at the time, the widow of Professor Bonham, and Valerie Smith, but none from the "other side".

In my own case, I have 12 archive boxes of material related to the inquiry.

Bryder makes the 1984 paper and my

writing a particular focus, attacking my conclusions as a kind of surrogate for the report itself. Bryder even goes to the extent of wrongly crediting me with particular actions taken by Phillida and other people. For example, I did not write to McIndoe, Jackie McAuliffe did; Professor Bonham wrote to Phillida, not me; I did not interview Dr Ralph Richart from New York, Phillida did; I did not interview Bonham alone, but with Phillida. These are not critical points, but a historian should be accurate and the correct information is easily available. Phillida, my co-author and colleague, gets expunged from the narrative, presumably so Bryder

can concentrate her case against me.

In building her case on prior sources, Bryder fails to acknowledge that the Cartwright Inquiry superseded everything. The inquiry had access to evidence that was not available for the *Metro* article, especially the patient files. The judge did not rely on the 1984 paper or the *Metro* article, but based her conclusions on primary sources. Yet Bryder builds her case around these earlier documents more so than the report itself. Perhaps in these post-feminist days, I am a "softer" target than a judge and former Governor-General of New Zealand.

# THE "TWO GROUPS" ARGUMENT

One particular claim made by Bryder needs addressing. She has repeatedly claimed that Phillida and I got it wrong about the 1984 paper and so did Cartwright. She says that although the two groups of patients in that paper were not Green's division, we claimed they were in *Metro*. Bryder says that because Green did not have two groups, he could not have been conducting an experiment. This has been repeated in all the media coverage subsequently. No one has checked this with me, and no one seems to have gone back and read our original *Metro* article.

Bryder is completely wrong in these allegations. Phillida and I spoke to all four authors of the 1984 paper. When we wrote the *Metro* article we understood perfectly that the study was retrospective and the division of groups was not Green's.

In fact, that the two groups in the 1984 paper were not Green's is irrelevant to Cartwright's finding that he was indeed experimenting.

Cartwright did not accept Green's denials in the witness box and concluded that he was conducting a trial. She had multiple reasons for deciding this, including that he had a stated research intention: his words were, "to attempt to prove that carcinoma in situ is not a premalignant disease"; he withheld conventional treatment from some women; he repeatedly stated he was following women with "adequately diagnosed but untreated lesions indefinitely"; and he published his results.

He wrote: "This series of 750 cases of in situ cervical cancer and the following of 96 of them with positive cytology for at least two years represents the nearest approach yet to the classical method of deciding such issues as the change or not of a disease from one state to another — the randomised controlled trial. It has not been randomised and it is not well controlled but at least it has been prospective..."

In other words, Green was conducting an experiment even if it was not conducted according to the "gold standard" for clinical research.

### GREEN'S INADEQUATE MANAGEMENT METHODS

Green's management of his patients has been variously called "inadequate", "unconventional" and even "non-treatment", all descriptions with which Bryder takes issue.

Bryder contends that because Green was doing lots of surgery, this is evidence he was treating women. She also argues that his treatment did not differ from that of other clinicians.

The accepted purpose of treatment for CIS at the time (as now) was to eliminate the disease, shown by the woman having normal (negative) smears afterwards.

But this is precisely what Green did not

DR GREEN PERFORMED SHOCKING AMOUNTS OF SURGERY ON SOME WOMEN.

do. Green did indeed perform shocking amounts of surgery on some women, but many of the women whom he recalled repeatedly to the hospital had successive high-grade abnormal smears and even microinvasion (an early stage of invasive cancer), often over years.

This management cannot be called treatment. Apart from a Japanese team, brought to the inquiry in Green's defence, no doctor at the inquiry said that this is how they managed patients.

Having viewed patient files, Green's own witness Dr Ellis Pixley, of St Anne's Hospital (now Mercy Hospital Mt Lawley) in Perth, said: "I was unable to agree to the method of management in any case." Similarly, Dr Joe Jordan, from Birmingham, one of the most eminent experts in this area to attend the inquiry, said: "I know of no other unit other than Professor Green's which was prepared to allow patients with carcinoma in situ to continue without treatment."

Jordan said Green had visited his and other units overseas. Green had been "adamant that what he was doing was an acceptable approach but was also aware that he was receiving worldwide criticism for his work". Bizarrely, Bryder repeatedly misuses quotes from Jordan in defence of Green's practices.

Even Green's great supporter Professor Dennis Bonham said after being disciplined by the Medical Council that he thought Green's conservative approach "bordered on fanaticism".

He said he had been shocked at Green's patient files, which he saw for the first time at the inquiry. He said he had stuck by Green at the inquiry out of loyalty. This awkward piece of information is simply omitted by Bryder.

# THE MATTER OF CONSENT

The lack of consent by the women in Green's study is also echoed in the "baby smears" study. Green began a programme to take vaginal swabs from girls under five days old, to test his theory that some females were born with abnormal cervical cells. Parents did not consent to his research, though Bryder disputes this.

Bryder ignores altogether the bizarre nature of this trial, and whether it was ever ethical. The sister who was required to run it and the cytologists were all unhappy about it and the doctor in charge of the cytology lab complained to Green.

Bryder concludes that mothers were told because one of the special-duties sisters who took the smears made a statement that she did. But that was only part of the information. Bryder overlooks the contesting evidence of other nurses involved that the permission of mothers "was not actively sought".

Cartwright herself concluded that "there was no provision to comply with the fundamental requirement that children are not included in research without the consent of their guardians".

Lowell Goddard, counsel to the inquiry and now a judge of the High Court, said of the "baby smears" that "the tone of the inquiries [to the inquiry] has generally been of some anguish by these mothers and young women born during that period of time". At National Women's, one gynaecologist discovered that his own daughter had been swabbed. Bryder ignores this confirmation that parents did not know.

## SILENCING THE WOMEN

On radio, Bryder went further than her book in questioning Cartwright's abilities. Cartwright "misunderstood", was "confused" and "got it wrong". This is put down to the apparent huge influence I singlehandedly had on the process. Cartwright "was very taken with the *Metro* article... I'm not saying she [Cartwright] came along with an agenda... she got handed an agenda."

As well, says Bryder, Cartwright had difficulty understanding the medical information and "she was interviewing women who had cancer — now it's a horrible disease and she's a very sympathetic listener and I think she was taken by that..."

So Cartwright is viewed by Bryder simultaneously as highly suggestible, lacking in intellect and emotional to the point of being swayed by meeting women with cancer. This would be laughable were it not so insulting to one of New Zealand's most eminent jurists, currently sitting on a United Nations tribunal in Cambodia examining the Pol Pot regime.

The fact that Cartwright made the patients central in her report was groundbreaking and explains the difficulty some doctors had in accepting it. The most striking thing about Bryder's account is her downplaying, even denial, of the women's experiences.

Bryder's book appears more concerned about professional reputations — she says she "did feel sorry for Herb Green" — than the women.

I was astounded to hear Bryder telling Kim Hill on Radio New Zealand National that Matheson ("Ruth" in the *Metro* article) is a "hale and hearty woman now with four children, and I think that has to be remembered" — in other words, didn't Green do a good job — without ever mentioning that Matheson developed cancer as a result of Green's management.

When Matheson confronted Bryder about the fact she gave birth to only one child after her referral to Green, not the four claimed by Bryder, Bryder apologised for getting it wrong but blamed her source, a letter to the Sunday Star by Jan Corbett, author of the debunking "second thoughts" article. In fact, Corbett's letter does not support Bryder's version - Corbett correctly said Matheson had one child. Bryder had not done what a historian should do, used primary sources - in this case, Matheson's own case notes contained in her book Fate Cried Enough - but had relied on a letter to the editor. Bryder preferred a second-hand, pro-Green account over the one Matheson could provide herself. Throughout the book, Bryder frequently prefers partisan sources to more reliable primary sources.

One of the important outcomes of the

BRYDER FREQUENTLY PREFERS PARTISAN SOURCES TO MORE RELIABLE PRIMARY SOURCES.

inquiry was the recall of women identified by Cartwright's medical advisers as needing further advice and possibly treatment. The knowledge that there were women with untreated disease was the main reason Phillida and I wanted the whole matter brought out into the open.

Cartwright's advisers started reviewing files from the beginning of the inquiry and, by early 1988, 139 women had been offered reviews by an expert independent gynaecologist.

Bryder says dismissively that "no dramatic consequences emerged from this exercise", echoing National Women's Hospital doctors who have claimed that none of the women who were recalled developed cancer.

The recall found that quite a few women, having moved away from Auckland, had got the needed treatment elsewhere, but of the women seen by the independent gynaecologist, around a quarter had to have further treatment.

Then, in May 1991, the Auckland Area Health Board, under pressure, finally disclosed that a death from genital cancer had occurred in one of the recalled women, and another had been diagnosed with invasive cervical cancer. This information is contained in a book I edited, yet Bryder ignores it and instead came to the cavalier conclusion that there were "no dramatic consequences".

The gynaecologist who saw the recalled women said he had never seen such mutilated genital organs, the cumulative result of the multiple biopsies Green performed as he followed these women year after year. One of the illogicalities of Green's regime was the large number of surgical interventions, often involving general anaesthetics, that he subjected women to.

This is not something that Bryder confronts. Bryder's contention that Green sought to minimise surgery is nullified by what happened in practice. Experts at the inquiry said they rarely did two cone biopsies on an individual woman, and had not heard of more. Green did three, four and even five.

The explanation for this, and the one Bryder avoids, is that Green was observing the lesions on women's cervices or vaginas for the purposes of research and from time to time removing small amounts of tissue surgically to check the stage of the disease. This is also why the hospital still holds a large archive of photographs of women's cervices he had taken while the women were under anaesthetic having biopsies, up until he retired in 1982. No consent to take these photographs was ever sought.

One of the most compelling pieces of evidence in the Cartwright Report is an appendix. It is a chart showing the development of invasive cancer in women who were treated for CIS at National Women's Hospital. Between the start of Green's trials and the mid-1970s when he stopped recruiting women, there is a dramatic spike in cases of invasive cancer. It is stark, tragic, an austere depiction of so much human misery.

In the final analysis, the truth of what happened to the women at National Women's cannot be explained away.

The Cartwright Report is now online at moh.govt.nz/moh.nsf/indexmh/cartright-inquiry.

The original 1987 Metro article and other documents can be seen at womenshealth.org.nz •