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# NEWSLETTER

APRIL • 2021

*a voice for women's health*

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## Our Health System in Crisis! and what the Government plans to do about it



*Plus*

Our Nation's Shame – Maternal Suicide | Challenging suggestions to honour Herbert Green  
Johnson & Johnson loses court appeal over mesh | Miscarriage Bereavement Bill  
Proposed bill amendment to allow safe areas around abortion facilities *and more*



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# Overhauling our Health System

## *the Government response to the Health and Disability System Review*

By Sue Claridge

*“Our system is under serious stress and does not deliver equally for all.”*

– Hon Andrew Little<sup>1</sup>

In June 2020, the final report<sup>2</sup> from the review of the health and disability system, commissioned by then Minister of Health, David Clark, and headed by Heather Simpson, was published\*.

The vision of the review panel was clear and simple: “to deliver a system that is a truly New Zealand system. A system which embeds te Tiriti principles throughout, where Māori have real authority to develop and implement policies which address their needs in ways which respect te Ao Māori, and a system where all New Zealanders, Māori, Pacific, European, Asian, disabled, rural or urban, understand how to access a system which is as much about keeping them well, as it is about treating them when they become sick.”<sup>2</sup>

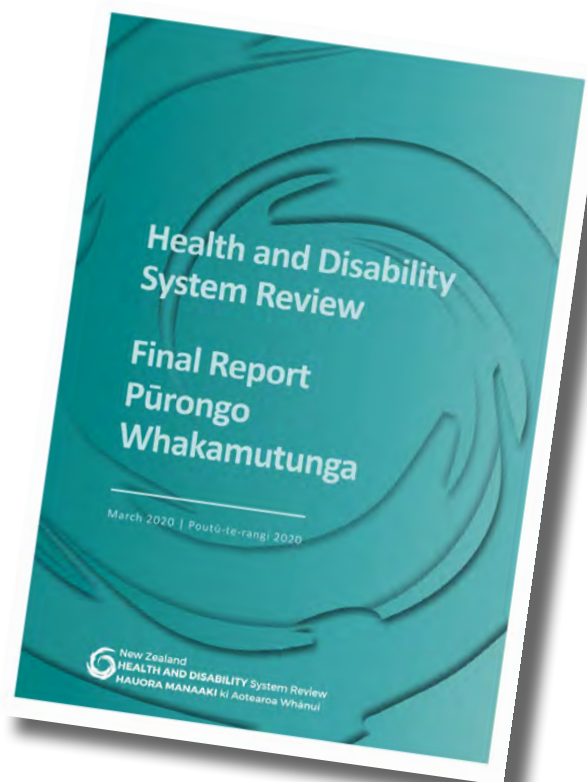
The Review panel was tasked with “recommending system-level changes that would be sustainable, lead to better and more equitable out-comes for all New Zealanders and shift the balance from treatment of illness towards health and wellbeing.”<sup>2</sup>

On the 24th of March this year Minister for Health, Andrew Little, told health sector representatives how the Government will set about delivering healthcare that is equitable and sustainable so more New Zealanders get the health services they need.<sup>1, 3</sup>

Mr Little said that the Government has been working since the 2020 election to “take the Review’s analysis and develop a proposal for the future to improve how we deliver healthcare” and he said that in April they would “announce the new shape and structure for the future health and disability system... [a] blueprint for how the system will work in the future.”

He also set out the vision for an overhauled health system:

“Our guiding vision is for a health system delivering pae ora/healthy futures for all New Zealanders,



where people live longer in good health and have an improved quality of life.”

“Our guiding vision is for a health system delivering pae ora/healthy futures for all New Zealanders, where people live longer in good health and have an improved quality of life.

If we are to realise this vision, the reforms need to focus on how we achieve five outcomes, above others. These are:

**Equity** for all New Zealanders — so everyone can achieve the same outcomes, and have the same access to services and support, regardless of who they are or where they live.

**Partnership** — through embedding the voice of Māori and other consumers of care into how the system plans and makes decisions, ensuring that Te Tiriti o Waitangi principles are meaningfully upheld.

\* for a summary and discussion of the report see the AWHC June 2020 Newsletter at <https://www.womenshealthcouncil.org.nz/>



**Excellence** — ensuring consistent, high-quality care is available when people need it, and harnessing leadership, innovation and new technologies to the benefit of the whole population.

**Sustainability** — focusing the health system on prevention and not just treating people when they are unwell — ‘wellness not illness’ — and ensuring that we use resources to achieve the best value for money.

*“Our guiding vision is for a health system delivering pae ora/healthy futures for all New Zealanders, where people live longer in good health and have an improved quality of life.”*

**Person and whānau-centred care** — by aiming to empower people to manage their own health and wellbeing and put them in control of the support they receive.”<sup>1</sup>

He went on to praise the current health system on how it performs on a range of measures while acknowledging that it is under increasing stress and fails to deliver equitably for all New Zealanders. He stressed that “First and foremost, we must make changes to tackle the persistent inequity in health outcomes.”<sup>1</sup>

He also mentioned the disparities in health for both disabled people and rural communities as well as or Māori and Pasifika.

More than once Andrew Little described our current health system as “fragmented” and lacking cohesion. He described a system that “has become complex and unnecessarily fragmented. Organisations have unclear or overlapping roles, responsibilities and boundaries. There is significant duplication of activity, and variation that creates a post-code lottery when it comes to accessing services.”

He believes that there are five key shifts that an overhauled health system must deliver:

1. **The health system will reinforce Te Tiriti principles and obligations** to address current inequities and provide a stronger voice and influence for Māori, including a new Māori Health Authority.
2. **People will have more support to help them stay well in their communities** through a better range of integrated primary and community services with increased access and protected funding to help them stay well.

3. **High quality emergency or specialist care when it's needed** to ensure equitable access through services planned to ensure the best distribution of care and equitable access across all regions.
4. **Digital services and technology will provide more care in people's homes and communities** building on the virtual care we saw during the COVID-19 response and providing more ways for people to access safe, quality and convenient services.
5. **Health and care workers will be valued and well-trained** ensuring we have enough trained people, resourced to provide better services for our communities.

Finally, Andrew Little acknowledged that the Government certainly does not underestimate the size or the complexity of the task and the need to “maintain services for our communities as we transition to the future.”

### ***It Is Imperative to Get it Right***

It is imperative that the Government gets this long overdue overhaul of the health system right; our current system is at breaking point (see page 6)



Minister of Health Andrew Little

Andrew Little says, “to build a better health system will require input from and partnership with organisations, groups, professions, patients and whānau.” He goes on to say that the “immediate need after Cabinet’s decisions will be engagement about how we get the details right.”

There are many failures and layers of issues that must be addressed. We not only need a health system that delivers equity and excellence, but we need a health system that is properly resourced and funded, that is able to address staffing shortages, particularly in nursing and midwifery.

We need a health system that is good enough to retain staff at all levels, rather than one that exhausts and burns out staff forcing them to leave. The changes need to extend to how we train and resource the people who staff all levels of the health system, for example training that addresses the acknowledged institutionalised racism seen in some of our DHBs. We need a health system in which delays in diagnoses and treatment are in the past; a health system in which there is a cultural shift in the provision of services so that complaints to the Health and Disability Commissioner drop year on year rather than rise.

It is important that this overhaul, in whatever shape and form the Government decides it must take, is completed; that a shiny new, functional, equitable and whole health system emerges. What we must avoid is a partially completed overhaul that is neither fully new and functional, nor old, flawed but familiar, because a half-renovated health system may well be worse than what we already have.

### ***Cross-Party Support Is Imperative***

It is critical that there is cross party support and commitment to change and improvement. In all likelihood it will take longer than the current term of government to achieve the health care system they are setting out to build. In the event that there is a change in government at the next election, an incoming government must be committed to continuing to implement the changes to the health system. There is precedent for incoming governments to undo the work of previous governments, to abandon initiatives in health. For example, the disestablishment of the original Cancer Control Council in 2015 — then Minister for Health Jonathon Coleman said at the time “its role has been superseded by the progress made in improving cancer services for New Zealanders.”<sup>5</sup>

The same National Government defunded and then abandoned the *Healthy Eating-Healthy Action: Oranga*

*Kai — Oranga Pumau (HEHA) Strategy*,<sup>6,7</sup> launched in 2003 by the previous Labour Government to address growing concerns over poor eating habits, lack of physical activity, and the associated prevalence of obesity and increased risk of adverse health outcomes that result. In 2009, they also disestablished Mission-On, a NZ\$67 million initiative by the Labour Government, charged with improving food and nutrition in schools and early childhood centres, promoting student health, and controlling television advertising.<sup>6</sup>

The recent announcement about a new midwifery initiative is a perfect example of why this health system overhaul is vital and urgent, and also illustrates the need to do this properly.

On the 30<sup>th</sup> of March, the Government announced a new initiative that aims to retain and attract more Māori and Pasifika to midwifery.<sup>8</sup> In part the initiative is aimed at boosting the midwifery workforce, but also the Government wants the midwifery workforce to reflect the “diversity of the mothers, babies and whānau they care for.”<sup>8</sup>

“Only about 10% of the total midwifery workforce are Māori and under 3% are Pasifika, while 20% of women giving birth are Māori and 10% are Pasifika.”<sup>8</sup>

This initiative is fantastic news and will not only boost the midwifery workforce overall but hopefully significantly improve pregnancy and birth outcomes and experience for Māori and Pasifika women. However, it is not enough to just train more midwives — although that is sorely needed. Part of the reason that we have staffing shortages in midwifery is that we are losing dedicated, trained women from the profession because maternity services across the board are underfunded and under-resourced, and midwives are inadequately supported and inadequately remunerated for the vital and difficult job that they do.

We need to ensure that we are not losing midwives because they feel that they or their mums and babies are unsafe, or because they feel unsupported or are burnt out and struggling to make a living. It is not enough to throw money at training new midwives no matter their cultural diversity, if our health system is so broken and dysfunctional that we cannot retain them.

The Government’s plan to overhaul the health system is a once in a generation chance to make very real changes at all levels of the health sector; to really ensure that our people live longer in good health and have an improved quality of life. The Auckland Women’s Health Council, and no doubt

# A Health System at Breaking Point

Our health system has been under extreme stress for many years, and recent reports suggest that parts of it are on the verge of collapse.

In recent years in this Newsletter we have covered a number of issues that are all symptomatic of a health system that is not coping with the health needs of New Zealanders:

- a chronic shortage of midwives with women leaving the profession in droves; loss of services in rural and provincial areas of the country; new mothers sent home from hospital before they are ready and short of the stay they are entitled to; severe and poorly addressed preventable illness in pregnant women;
- racial disparities and inequities in almost every area of health services, from access to service provision to outcomes;
- increasing cancer incidence, and delays in diagnosis and treatment; delays in changes to the cervical screening programme and implementation of the cervical screening register; delays in the diagnosis of colorectal cancer leading to poor outcomes;
- the surgical mesh crisis that is ongoing;
- breaches of patient rights, in particular informed consent rights, and year on year increases in complaints to the HDC indicating no cultural shift among health practitioners or improvement in the quality of health services provision;
- DHBs not coping with demand for services.

In March 2021 alone there were multiple reports in the media on the dire state of certain areas of the health system, including:

- Two recent surveys from the Royal New Zealand College of General Practitioners have signalled real concern about an increase in GP burnout, the number of GPs intending to retire, and the sustainability of the sector.<sup>9</sup> Three main issues were identified including patient complexity and more patients presenting with mental health issues; the outdated 15-minute appointment model that doesn't allow for addressing complex needs, but this is how GPs are funded; and relentless mountains of paperwork that must be completed outside consultation time. GPs are struggling with both their workload and how to keep themselves well.

On the 10th of March, MP Louisa Wall told the parliamentary health select committee's annual review of the Counties Manukau DHB that it has been chronically underfunded, missing out on well over \$500 million over the past 21 years. "You [CMDHB] haven't received your fair share, from an equity perspective of the money that the Government allocates to serve the population you serve."<sup>10</sup> The same annual review of the DHB was told that CMDHB is "short 150 nurses, a revelation the New Zealand Nurses Organisation is calling outrageous."<sup>11</sup>

- Numerous reports have described overwhelmed and crowded hospitals unable to cope with demand. A woman who took her elderly father who had a brain bleed to the Waikato Hospital emergency department, only to wait 16 hours for treatment.<sup>12</sup> While there the woman helped another physically ill elderly patient because there were no staff available to tend to her. In the same report a Wellington GP said the emergency department struggles were symptomatic of the struggles the whole health system is facing. "There's no beds, referrals that we're sending through are being declined. Even when patients are in the system and they've been seen by a specialist they're not followed up with it. Referrals for imaging aren't getting done on time. If they do get listed for surgery they wait months and months."<sup>12</sup>
- On the 24<sup>th</sup> of March, Dunedin Hospital declared a 'code black'<sup>†</sup> because it had reached full capacity. Whangārei Hospital had also reached capacity and Australasian College for Emergency Medicine president Dr John Bonning said the emergency department was where the stress was most visible, but the whole system was under increasing pressure. He went on to say "Virtually everyone I have spoken to has issues with this. We've had the biggest January and February on record."<sup>14</sup> In the same report, College of Emergency Nurses chair Sue Stebbings said the crisis point had been building for years. New Zealand Medical Association chair Dr Kate Baddock said the issue "did not

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<sup>†</sup> hospital at capacity – no available beds for new admissions from A&E. A code black is declared by the hospital's general bed manager, who then relays this to the local ambulance service and posts updates for local healthcare services such as GPs and district nursing teams.

start with emergency departments, that was just where it was most visible.” GPs were overwhelmed with increased workloads, not enough doctors, more patients, and not enough support, she said. That was leading more people to go to EDs as they faced waiting times of up to four weeks to see their GPs.

- A press release issued by the General Practice Owners Association on the 31<sup>st</sup> of March said that “the pressure on EDs is just one of the consequences of poor whole-of-system planning and a lack of appropriate resourcing to manage growing demand from an increasing and aging population. Over a number of years, general practices across the country have been expected to manage the care of more and more patients whose needs would have historically

been met by specialist hospital services. That continuing shift of care to general practices has come without additional resources or support.”<sup>15</sup> They go on to say that this mounting pressure on the EDs and GPs is “indicative of how the health system is failing New Zealanders.”

- The Association of Salaried Medical Specialists says frontline mental health workers are overwhelmed by skyrocketing demand and have seen no meaningful progress despite the promises of the 2018 mental health inquiry. In assessing progress on the recommendations from the inquiry, the Mental Health and Wellbeing Commission describes frustration over the pace of change and the speed at which funding is being delivered.<sup>16</sup>

many other NGOs around Aotearoa New Zealand — organisations that see some of the worst outcomes from our broken and dysfunctional health system — await these changes with bated breath and much hope for the future.

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# Our Nation's Shame – Maternal Suicide

## and the Perinatal and Maternal Mortality Review Committee Report

By Sue Claridge

*Ki ngā pēpi kua ngaro ki te pō, moe mai koutou. To our precious ones who have disappeared into the night, rest in peace. I acknowledge our precious babies, our grief and our journey.<sup>6</sup>*

— Lisa Paraku (Ngāti Tamaterā, Ngāti Porou),

Kaiohu Matua Māori — Chief Advisor Māori Health, Whānau Āwhina Plunket

It is no secret that New Zealand has a tragically high suicide rate, and we have the highest youth suicide rate in the world.<sup>1</sup> It has been widely described as “our national shame” for many years.<sup>2, 3, 4</sup>

Sadly, we can add heartbreaking maternal suicide to that national shame; on average at least 10 women\* die in Aotearoa New Zealand every year during pregnancy or in the months after birth.<sup>5</sup> “Experts say that’s the ‘tip of the iceberg’ as many such deaths go unreported.”<sup>5</sup>

In reporting on perinatal and maternal mortality for 2018, the Perinatal and Maternal Mortality Review Committee (PMMRC) write that:

“Wāhine Māori have statistically significant higher rates of maternal mortality than New Zealand European women. While there were no deaths by suicide in 2018, this remains the single largest cause of maternal death in Aotearoa/New Zealand, with suicide accounting for 44 percent of direct causes of maternal death since 2006.”<sup>6</sup>

Between 2006 and 2018 there were 30 maternal deaths by suicide reported by the PMMRC.<sup>6</sup> In comparison with the UK, we have five times the maternal suicide rate, while the differences in other causes of maternal death between the two countries were statistically insignificant.<sup>6</sup>

While the majority of maternal suicides occur in the postpartum period (56%), a significant proportion occur during pregnancy (41%)<sup>†</sup>. The PMMRC say that “in contrast to previous thinking, pregnancy is not necessarily protective of death by suicide.”<sup>6</sup>

This 14th report of the PMMRC does not, however, provide a complete and up-to-date picture of maternal

suicide in New Zealand. The PMMRC only consider deaths up to 42 days postpartum; the New Zealand Herald reported that “one in seven new mums suffer postnatal depression after giving birth”<sup>5</sup> and the issue may have escalated in the year of Covid, particularly for mums giving birth during lockdown in 2020. Emma Russell reported that “first-time mums have described being left alone after traumatic births during lockdown,”<sup>7</sup> a period of time when women were left without the support of partners and whānau during labour and birth because of visitor restrictions owing to the pandemic.

Chole Wright, founder of advocacy group Mothers Matter, said maternal suicide was a crisis which has been escalated by Covid-19.

“We are very complacent as New Zealanders and we become almost accepting of all of these deaths. We don’t hear too much about the women, we only hear about the babies who are murdered.”<sup>6</sup>

Ms Wright and Mothers Matter partnered with Canadian film-makers Moonlight, to show the extent of maternal suicide and postnatal depression in New Zealand in a film that was shown to MPs on the 10<sup>th</sup> of March.<sup>6</sup> Politicians, including Health Minister Andrew Little, Minister of Women Jan Tinetti, Act leader David Seymour, National MPs Simon Bridges and Louise Upston, were left stunned by what they saw.<sup>5</sup>

\* This is higher than the rate reported in the *Fourteenth Annual Report of the Perinatal and Maternal Mortality Review Committee*, but this could be due to different definitions of maternal death, with the PMMRC only considering death up to 42 days post-partum, while broader post-natal maternal suicide (e.g as a result of postnatal depression covers a longer period)

† Three percent of maternal deaths occurred during the intrapartum period or the timing was unknown.



Mothers Matter have launched a nationwide campaign to protest “against women being discharged from hospital after giving birth without any support, a postcode lottery for maternal care, lack of wraparound services for struggling mums, and cultural and economic barriers for new mums to get help.”<sup>5</sup>

Those who spoke alongside Ms Wright at the campaign launch at Parliament included science adviser Sir Peter Gluckman, wellness advocate Gemma McCaw, paediatrician Dr Johan Morreau, mum and advocate Joanne Rama, and midwife Tish Tahia.

The film, which had been shown on TV after the launch, was subsequently the subject of 13 complaints to the Advertising Standards Authority, which ordered it off air, sparking widespread outrage. On social media, commenters were furious at what they saw as attempts to sweep suicide under the rug and pretend it doesn’t happen, and said it was an example of women being silenced yet again.<sup>8</sup>

Act MP, David Seymour, one of the first to see the film when it screened at Parliament, was outraged at the ban, saying “If we can’t have an honest conversation about [maternal suicide], I don’t know what we can talk [sic] about it.”

He went on to say that “the simplest thing the Health Minister could do was come out and say ‘I want every woman in New Zealand to know that you have a right to 48 hours care after giving birth’”.<sup>8</sup>

Depression and anxiety are the most common mental health issues experienced by women during the perinatal period; a New Zealand study in 2009 found that out of 5,664 pregnant women, 12% had symptoms of depression in their third trimester.<sup>9</sup> Depression in the third-trimester was 1.2 times higher in wāhine Māori, 1.9 times higher in Pasifika women and 2.4 times higher in Asian women,

compared with women of European ethnicity.<sup>9</sup> A 2015 study on postnatal depression in New Zealand found that 14% of new mothers suffered from postnatal depression.<sup>10</sup>

The PMMRC expressed its utmost concern at the “alarmingly higher rates of maternal suicide that Māori whānau are experiencing.” They asked that “recommendations that create a Tiriti-compliant system where it is safe for Māori women to give birth in Aotearoa/New Zealand” be prioritised. They also called on the Ministry of Health to prioritise investment in maternal and infant mental health.<sup>6</sup>

In its 11<sup>th</sup> report in 2017 the PMMRC recommended the HQSC establish a permanent Suicide Mortality Review Committee.<sup>11</sup> That report found that among wāhine Māori who committed suicide perinatally, half had self-harmed or attempted suicide prior to or during the final pregnancy, and that nearly half of the women in the review identified as having mental health issues were either not referred to mental health services, or it is unclear if a referral was made or appropriately acted on.<sup>11</sup> They say that that “repeat themes arising in recent maternal suicide reviews include lack of recognition of the risk for pregnant women presenting with suicidal ideation and failure to refer promptly for assessment and treatment.”<sup>11</sup>



*"...among wāhine Māori who committed suicide perinatally, half [have] self-harmed or attempted suicide prior to or during the final pregnancy..."*

The loss of any person to suicide is a tragedy for the individuals and their family and friends. That we lose so many young women, predominantly wāhine Māori, during pregnancy or soon after birth is more than a tragedy; it is an indictment on our health system and mental health services, and a sad commentary on our society that women suffer so much at a time in their lives, that otherwise should be full of joy and optimism, that they feel suicide is their only option.

## Other Figures from the PMMRC Report<sup>6</sup>

Overall fetal and early neonatal deaths (perinatal mortality) have decreased since 2007 when the PMMRC began collecting data. However, the reduction is entirely among babies of New Zealand European mothers, but not for any other ethnic group.

The decrease in the rate of stillbirths was largely driven by a reduction in stillbirths in babies of New Zealand European women. There was also a statistically significant decrease in stillbirths for babies of Middle Eastern, Latin American, or African (MELAA) women, but no significant change occurred in any other ethnic group.

Deaths due to congenital anomalies remain the leading cause of death overall. The rates of perinatal-related mortality in the peripartum period due to hypoxia have decreased significantly since 2007.

Babies of Māori, Pasifika and Indian mothers, and babies of mothers aged less than 20 years, are at higher risk of serious adverse outcomes.

Risk of perinatal death also increased when the maternal age was 40 years and over. Mortality rates from stillbirth, neonatal death and perinatal related death overall increase with increasing maternal BMI. Rates of mortality from stillbirth, neonatal death and perinatal related death overall were higher for babies of women who were smoking at the time of registration with a lead maternity carer (LMC) compared with those who were not — smoking is a significant and modifiable risk factor of perinatal loss!

Poverty or low socioeconomic status is also a risk factor. Perinatal mortality rates varied significantly by the level of socioeconomic deprivation in the areas where mothers lived, as measured by the New Zealand Index of Deprivation 2013. Those mothers living in the most deprived areas (quintile 5) were statistically significantly more likely to lose a baby from stillbirth, neonatal death and perinatal related death overall, compared with those living in any other quintile. This variation in mortality rates by deprivation was most marked for deaths due to spontaneous preterm labour or rupture of membranes.

Overall, around 41% of babies who died had optimal investigation into the cause(s) of their death, meaning that their death was investigated through post-mortem, karyotype confirming chromosomal abnormality or clinical examination or investigation confirming the diagnosis. Around half of terminations of pregnancy had 'optimal' investigation, whereas under 40% of stillbirths and neonatal deaths did.

The PMMRC states that "it is unacceptable that, yet again, it is babies of Māori, Pacific and Indian women who are over-represented within the data in this report. Also, it is of great concern to the PMMRC that this inequity could further increase as a result of barriers to accessing care during the response to the COVID-19 pandemic."

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# 2020: the Auckland Women's Health Council Annual Report

In 2020, the year of the Covid 19 restrictions, the Council continued to meet, produce bi-monthly newsletters, discuss, and write submissions, and provide a voice for consumers where women's health issues and those related to informed consent have arisen. Throughout the year we have had to change and adapt to our changing environment during 2020.

In March, Danika Revell took on the management of many elements of the co-ordinator role on an interim basis. She also researched and presented a proposal to the AWHC executive committee with suggestions on how to modernise and streamline the executive committee communications and re-define the organisation for 2020. Danika left this role in November but has remained a very active member of the executive committee, continuing to provide significant support. As a result some key roles previously provided by the co-ordinator have been undertaken voluntarily by committee members.

Emphasis throughout the year has been on maintaining newsletter production, re-designing and updating the AWHC website and social media updates, being available for comment when the media picked up issues and developing a strategy to implement in 2021 when anticipated funding will enable the Council to appoint a paid co-ordinator again.

## Meetings

The Council holds a general working meeting each month to discuss the current projects the Council is working on; make decisions on particular health issues the Council is dealing with; discuss grant applications and financial matters pertaining to the operation of the Council; and to deal with the ongoing work of the organisation.

The Council continues to establish *ad hoc* subgroups to work on issues as they arise, such as preparing submissions. Consequently, at our monthly meetings detailed reports from the treasurer, newsletter editor Sue Claridge, members and subgroups are presented and discussed.

During the Covid -19 lockdowns the Council met using videoconferencing services such as Zoom to conduct monthly business meetings. Whenever possible, face to face meetings were scheduled and these meetings were complemented with Zoom connections for members otherwise unable to attend.

On August 5<sup>th</sup>, we met with members of the Cartwright Collective to commemorate the release of Judge Sylvia Cartwright's Report into the treatment of cervical cancer at National Women's Hospital, and lay flowers in memory of the victims and their whānau, including the 33 women who died as a consequence of receiving inadequate treatment.

## Funding

Given the impact of COVID 19 on communities and organisations we were gratified to receive funding from the four greater Auckland COGS committees. An administrative mix-up with our grant application meant our Lotteries Community July funding request was not considered until we resubmitted it for the December funding round. While we were successful in being granted \$20,000 of the \$28,000 requested this funding was not received until March 2021.

Our total income for 2020 was somewhat less than we would ordinarily expect and as a result our intention to recruit a new co-ordinator position was again put on hold. Instead, we have appreciated Danika Revell's willingness to take on a variable part-time contract to cover aspects of this role in 2020.

## The AWHC Newsletters

The Auckland Women's Health Council newsletter is an important link with our collaborators (such as the Cartwright Collective and Mesh Down Under), and other women's groups, as well as with individual women. The Council continues to receive very







positive feedback on the newsletter including feedback from academics and students in the health sector, as well as readers who are consumers and consumer/patient advocates. The newsletters are made available on the website.

The production of the newsletter has continued to be a key function of the Council, and fortunately Sue Claridge has continued to produce bi-monthly newsletters on a contract basis, supported by the Newsletter sub-committee. In 2020, the Council published four newsletters and provided information on a range of women's health issues including researched articles on:

- breaches of informed consent rights in our DHBs and hospitals;
- racism in our health system;
- an AWHC review of the Health and Disability System Review;
- the gendered impacts of Covid-19;
- the HDC and whether or not it has fulfilled its promise;
- women's health through the centuries and attitudes to women's bodies and health and well-being;
- rheumatoid arthritis as a women's health issue;
- the harm wrought by surgical mesh.

In addition to topics above, the pre-election September edition of the newsletter was an in-depth review of the health issues that we believe must be a priority for the Government in the current term:

- inequities and disparities affecting Māori, Pasifika and women with disabilities.
- ongoing issues around facilitating patients to provide truly informed consent to medical tests and procedures as provided for in the Code of Rights.
- flaws in the Health and Disability Commission

and complaints process.

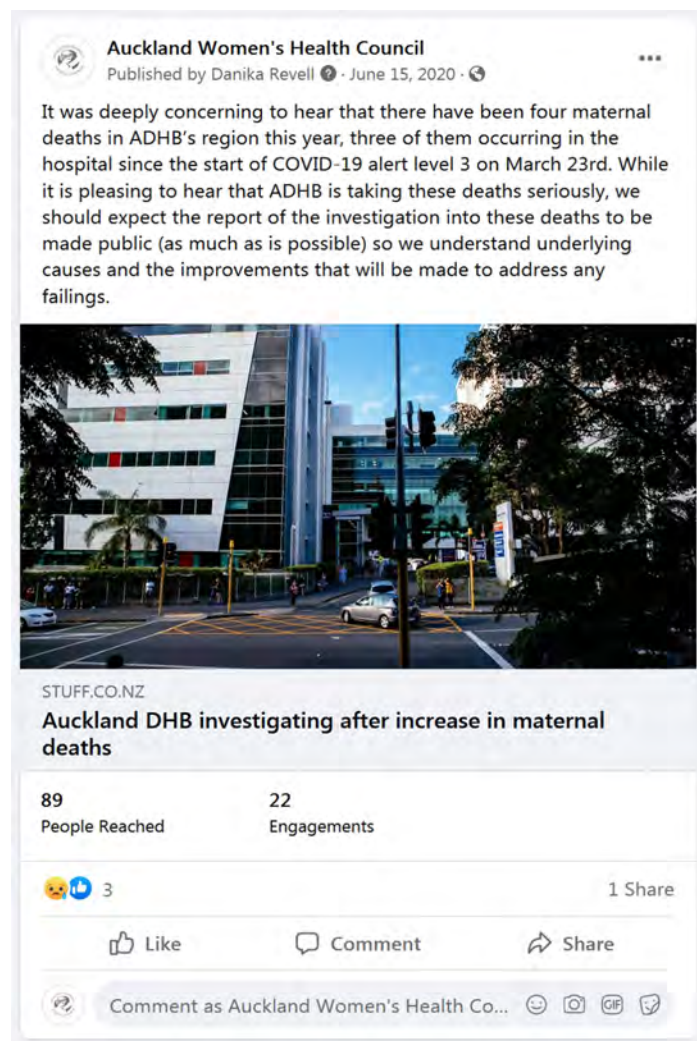
- the inadequate response to the surgical mesh crisis.
- issues in the provision of maternity services.
- the impact of socio-economic factors and poverty on health.
- consumer representation and engagement of consumers with their own health, health policy and the DHBs.

The manner in which we distribute and make available the AWHC newsletter is currently under review and changes are expected to accompany the website upgrade in 2021.

## Website and Facebook

The Council's Facebook page continues to engage with the community by providing feminist commentary and analysis of current health issues for women.

Hot topics that achieved high levels of engagement in 2020 included the 32nd Anniversary of the release of the 'Cartwright Report' and AWHC's visit to The Spirit of Peace statue at the old National Women's Hospital (now the Greenlane Clinical Centre). Another hot topic was our analysis and promotion of



surgical mesh victim Renate Schutte's petition urging change to the Health and Disability Commissioner Act to allow for the appeal of complaint decisions.

Facebook activity has increased during 2020. Not surprisingly the biggest group of visitors are women (92%) and from Auckland; mostly in the 25-34 and 35-44 age groups. The number of people impacted/reached via Facebook increased by 105% (from 1835 in 2019 to 3768 in 2020).

The website has been kept updated with Covid-related links, issues of the Newsletter (all newsletters from February 2012 to the present), written submissions and letters on a variety of women's health and patient rights issues.

During 2020 the website received 5,299 visits from 5,272 unique visitors, 4,389 new visits and 910 returning visits. Total annual visitor numbers have increased by 1139 compared with 2019, and the average daily visitor number has increased from 11 to 14 per day. The top ten topics that visitors sought information on were:

- cervical cancer
- abortion
- free access to the emergency contraceptive pill
- Essure contraceptive device
- the legacy of National Women's Unfortunate Experiment
- Cartwright Inquiry
- A2 milk story
- breastfeeding/result of complaint to ministry of health compliance panel
- Gardasil
- breast implants.

By their very nature, websites are always a work in progress and review, and we are currently engaged in an update/upgrade of the website which will continue in 2021.

## ***Collaboration***

AWHC has continued to collaborate with the co-convenors of the Federation of Women's Health Councils, MeshDownUnder (a support group for those injured by surgical mesh), the Cartwright Collective, the CCS Disability Action's Health & Wellbeing group, and the Period Place (an organisation that works to end period poverty). Requests for ongoing participation in the healthAlliance Consumer Group are being considered for 2021.

In 2020 The AWHC increased its support for Cartwright Collective meetings and activities relating

to the following issues:

- a face-to-face update from the National Screening Unit on progress on the NZ Cervical Screening Programme;
- raising the issue of DHB adherence to the requirements for informed consent when trainees and students are involved in treatment;
- a Health and Disability Commission forum, starting with a meeting with the new Commissioner;
- addressing the lack of legal obligation for participant compensation when trials are funded by pharmacy companies;
- development of an enhanced website as a repository for all documents, references, resources, and accurate information relating to the Cartwright Inquiry.

## ***DHB and Ethics Committee Meetings***

Reduced capacity has meant that fewer DHB and no Ethics Committee meetings were attended in 2020. We consider this an important function for the Council and will be ensuring our attendance restarts following the appointment of a co-ordinator.

## ***Submissions and Advocacy***

Each year the Council makes written submissions and attends consultation meetings on a variety of health issues that affect the health of women and patient rights. Submission that that AWHC has made in the last year included the Smoke Free Environments and Regulated Products (Vaping) Amendment Bill.

## ***The Future***

Danika Revell presented a proposal based on her review in June 2020 and a further strategy meeting was held in January 2021. The review included plans to maximise the usefulness of the AWHC website and the Facebook page and the intention to use current technology to offer Women's Digital Health Webinars. This will be pursued when the Council has a paid co-ordinator, drawing on our network of experts and researchers, as well as our own committee members to increase awareness and debate around women's health issues on a regular basis; a space where anyone on any device can participate.

The Council has also identified opportunities for new and active members who may be able to contribute to key tasks in 2021 and a likely timeframe, based on funding, for re-establishing the role of Co-ordinator.

# Another Attempt to Rewrite History: *challenging suggestions to honour Herbert Green*

By Sue Claridge

It is not the intention of this article to debate the scientific merits (or absence of) of the research undertaken by Dr Herbert Green on women with cervical abnormalities and *carcinoma in situ* (CIS) at National Women's Hospital in the 1960s and 70s.

The issue is the failure of some academics, health professionals and writers to accept that what Green did was ethically wrong. For those people to persist in re-writing history in attempts to 'beatify' and honour the man is grossly offensive to the women upon whom he experimented – some of whom died – and their families, those of Green's contemporaries who were horrified by his practices, the women who first shone a light on his 'unfortunate experiment', those who gave evidence at the Cartwright Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital<sup>1</sup>, and those who have worked since to protect and uphold the rights of patients.

Over the years there have been a number of attempts to "rewrite" history, to denigrate and dismiss the Cartwright Inquiry and its outcomes and recommendations, to discredit Sandra Coney and Phillida Bunkle who wrote the article 'An Unfortunate Experiment at National Women's' published in *Metro* magazine in June 1987, and to posthumously restore Herbert Green's reputation.

On each occasion these attempts have been met with a combination of outrage, disbelief, protest and condemnation. The disputing and defence of the Cartwright Inquiry, and of Green's research are well documented in the medical literature, and a number of responses to the revisionist writings can be found on the AWHC website.\*

## 2020 Papers in the Journal of Clinical Epidemiology

The most recent of these revisionist writings are two papers published in the June 1, 2020, edition of the *Journal of Clinical Epidemiology (JCE)*.<sup>2, 3</sup> While this AWHC article doesn't set out to discuss the merits or otherwise of Herbert Green's science, both *JCE* papers also discuss the ethics of his experiment. The papers present the argument that the ethical principles



acceptable in the 1960s cannot be measured against ethics acceptable in the 21<sup>st</sup> century:

"Regarding 1960s research, university medical staff were expected to use their clinical practice to further medical science and the prevailing view was that doctors knew best. Research ethics committees were rare."<sup>2</sup>

While that is strictly true, it is disingenuous to suggest that the environment was such that informed consent was a foreign concept. In 1966, when Green started his research at National Women's the Nuremberg Code was 19 years old and the Declaration of Helsinki (see page 17) two years into its influence on the ethics of medical research.

Raffle and Gray's paper states that "The 1964 Declaration of Helsinki, which differs from the 1983 version, required patient consent 'if at all possible, consistent with patient psychology,' but consent did not need to be written."<sup>2</sup>

For a man of Herbert Green's supposed intellect and purported character, to suggest he was entirely unaware of the Nuremberg Code and Declaration of Helsinki seems somewhat incongruous. While it might not have required consent in writing as would be the case today, it is difficult to argue that the women

\* <https://www.womenshealthcouncil.org.nz/Features/Cartwright+Inquiry.html>



# *The Nuremberg Code and the Helsinki Declaration*

The Nuremberg Code originated from the Nuremberg Trials held after the end of World War Two and in response to the atrocities on human beings committed by the Nazis in name of “science”. The Doctors’ Trial (also known as the Medical Trial) involved US physicians working with US lawyers to “prosecute Nazi physicians for murder and torture done under the guise of human experimentation.”<sup>10</sup>

The Code’s first principle states:

The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision. This latter element requires that, before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person, which may possibly come from his participation in the experiment.<sup>11</sup>

The Code’s second principle places the onus for obtaining consent squarely on the shoulders of the principle investigator or researcher:

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.<sup>11</sup>

Jay Katz, who was considered the world’s leading authority on the Nuremberg Code’s consent requirement, wrote that the consent principle of the Code was “stunning and uncompromising on respect for persons”.<sup>10</sup>

The Nuremberg Code is regarded as the “most important document in the history of the ethics of medical research.”<sup>12</sup> While the Code was never officially adopted as law by any nation or as ethics by any major medical association, its “basic requirement of informed consent, for example, has

been universally accepted” and the Declaration of Helsinki proclaimed by the World Medical Association in 1964, implicitly acknowledges the Code’s authority.<sup>12</sup>

The World Medical Association (WMA), of which New Zealand is a member, developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects.<sup>13</sup> First adopted by the 18th WMA General Assembly, in Helsinki, Finland, in June 1964, the Declaration was amended nine times from 1975 to 2013.<sup>13</sup>

In 1964 (and at the time that Herbert Green was undertaking his research into the development of cervical cancer) the relevant clauses of the Declaration of Helsinki include:<sup>14</sup>

## II. CLINICAL RESEARCH COMBINED WITH PROFESSIONAL CARE

1. ... If at all possible, consistent with patient psychology, the doctor should obtain the patient’s freely given consent after the patient has been given a full explanation. In case of legal incapacity, consent should also be procured from the legal guardian; in case of physical incapacity the permission of the legal guardian replaces that of the patient.

## III. NON-THERAPEUTIC CLINICAL RESEARCH

2. The nature, the purpose and the risk of clinical research must be explained to the subject by the doctor.

3a. Clinical research on a human being cannot be undertaken without his free consent after he has been informed; if he is legally incompetent, the consent of the legal guardian should be procured.

3b. The subject of clinical research should be in such a mental, physical and legal state as to be able to exercise fully his power of choice.

3c. Consent should, as a rule, be obtained in writing. However, the responsibility for clinical research always remains with the research worker; it never falls on the subject even after consent is obtained.

4a. The investigator must respect the right of each individual to safeguard his personal integrity, especially if the subject is in a dependent relationship to the investigator.

4b. At any time during the course of clinical research the subject or his guardian should be free to withdraw permission for research to be continued.

that Green involved in his research were inadequately intellectually or psychologically equipped to provide informed consent, albeit verbally.

Raffle and Gray point out that “Evidence to the [Cartwright] Inquiry from patients and staff testified to the quality of Green’s care and to his kindness”; that “Dr Green was a person who cared intensely about his patients”.<sup>2</sup>

He has also been described as charming and charismatic, and some of his patients adored him,<sup>4</sup> but charm and charisma do not absolve a medical researcher of the duty of care and obligation to inform patients of the fact that he was experimenting on them and obtain their consent to do so.

The second of the two papers in the *Journal of Clinical Epidemiology*, by Iain Chalmers,<sup>3</sup> is written very much in the same vein as the Raffle and Gray paper. He engages in a semantic argument, that there was no ‘experiment’, however, there is no doubt that research was undertaken. It is well documented and directly quoted in Judge Silvia Cartwright’s Report from the Minutes of the Senior Medical Staff Meeting, using words such as “proposal” and stating that “his aim was to attempt to prove” his hypothesis.<sup>1</sup> That he had a theory or hypothesis to “prove” about the progression of cervical abnormalities to invasive cancer identifies his treatment (or lack thereof) as observational research or a form of experiment.

Further proof of the experimental or research nature of Green’s work is his tests on healthy newborn baby girls (see sidebar). Chalmers doesn’t discuss this aspect of Green’s research, either because he isn’t aware of that part of Green’s history, or chooses to ignore it no doubt because it would not fit with his narrative of a brilliant clinician with only patients’ best interests at heart. Chalmers claims that Green’s work was not experimental, merely

## The Babies

Beyond the dire outcomes from Green’s research on women with cervical abnormalities, the *JCE* and other authors ignore the experimentation that he carried out on newborn baby girls starting in 1963, a full three years before his proposal to undertake clinical research on women at National Women’s Hospital in 1966. Green had developed somewhat of an obsession with the idea that abnormal cervical cells were present as early as in utero and had examined tissue samples from female stillbirths and neonatal deaths. But this was not enough, and he began research on healthy newborn girls.<sup>5</sup>

Ron Jones writes:

“In another study... he organised nursing staff to collect vaginal cells. Taken with small swabs, from healthy newborn girls, to test for abnormal cells. These tests were performed without the knowledge of the mothers.”<sup>5</sup>

In his evidence to the Cartwright Inquiry, Green said “that he had lost interest in this trial after 200 babies had had smears taken.\* Unfortunately his decision not to continue the trial was not communicated to the nursing staff and the trial continued until smears had been taken from 2244 new-born babies. There was no system in place that ensured that the trial stopped.”<sup>1</sup>

Dame Silvia Cartwright wrote:

“An effective system for monitoring research and ensuring that unnecessary procedures are not conducted, should have been in place. If this had been so, then more than 2000 babies would not have been subjected to a useless and possibly damaging procedure. Moreover, there was no provision made to comply with the fundamental requirement that children are not included in research without the consent of their guardians... this was clearly a trial and not part of the day-to-day care of the babies concerned. It was non-therapeutic, clinical research.”<sup>1</sup>

This author acknowledges that this research started a year before the adoption of the Declaration of Helsinki, however, even basic morals were absent in this case. Newborn baby girls were vaginally swabbed and tested for cervical abnormalities without their mothers’ knowledge or consent, and no records were kept,<sup>6</sup> nor did Green report his findings.<sup>5</sup>

That no records were kept of the babies that were tested<sup>6</sup> is particularly concerning. Without knowing who the babies were that were tested we have no way of knowing if there were any adverse impacts resulting, perhaps years later, from the invasive procedure on hours old babies. How can we know if any of those 2244 girls, who would now be between 55 and 58 years old, went on to suffer any vaginal or cervical issues? If any women born at National Women’s Hospital during that time have experienced vaginal and/or cervical health issues, chances are they have no idea that this research even took place let alone whether or not they were one of the tested babies.

\* Ron Jones writes that all of the tests on babies were negative for cervical cell abnormalities.<sup>5</sup>

‘conservative management’ of women with ‘cervical cytological abnormalities’.<sup>3</sup> How then, would Chalmers justify the taking of vaginal swabs from newborn baby girls on the basis of it being acceptable medical management? How is that not research; how is it not experimental?

One of the Terms of Reference of Judge Cartwright’s inquiry into the treatment of cervical cancer at national Women’s Hospital was to answer the question, “Was there a research programme?”<sup>1</sup>

Judge Cartwright wrote in her report that witnesses in the proceedings varied in their views: “Some took the view that it was not a research proposal but a move to treat patients more conservatively. Others were clearly of the view that it was a research proposal, albeit a poorly designed one.”<sup>1</sup>

Nine pages of the Cartwright report are devoted to the question of whether Green’s work was research (Chapter 3, pages 61-69). Judge Cartwright concluded:

“It was an attempt to prove a theory that lacked scientific validity and little attention was given to ethical considerations. From 1966 and throughout the period of the 1966 trial, there were clear guidelines against which a doctor’s moral and professional right to include patients in research trials could be measured. I can think of no reason for gynaecologists who practised at National Women’s Hospital or in other parts of New Zealand, or administrators whose responsibility it was to be familiar with ethical principles, to overlook the basic ethical and scientific information that was then available.”<sup>1</sup>

In his paper, Chalmers goes further than Raffle and Gray with his ongoing criticism of Sandra Coney and Phillida Bunkle, the Cartwright Inquiry and many of the academics and epidemiologists and doctors who gave evidence (David Skegg, Charlotte Paul, Ron Jones, *et al.*) in that inquiry.

In his conclusion, Chalmers writes that “a public apology to Herbert Green is long overdue” over “unsubstantiated allegations that his practice in the 1960s was unethical.”<sup>3</sup>

He goes on to suggest that Herbert Green be honoured with the establishment of an international Herb Green Prize, “preferably jointly by epidemiologists in New Zealand and individuals who owe their very existence to conservative management of “cervical carcinoma in situ” at National Women’s Hospital.”<sup>3</sup>

This proposal must be especially galling to the surviving women and the families of those women who died as a result of inadequately treated cervical abnormalities.

## ***The Response to the 2020 Journal of Clinical Epidemiology Papers***

The responses to the Raffle and Gray, and Chalmers papers in *JCE*, subsequently published in that journal, are divided between those in full support of and those disputing the conclusions of those papers. To cover these responses in detail here would be long-winded and run the risk of descending into a “he said, she said” style of discussion.

However, it is worth noting a few comments from those defending the Cartwright Inquiry and its conclusions and outcomes:

Sandra Coney and Phillida Bunkle respond to criticisms by pointing out that they, and their legal counsel and medical adviser, had access to the women’s medical files and over 80 interviews of patients, and conducted many interviews with most of the personnel involved, including Green and his superior Professor Denis Bonham, which Raffle and Gray, and Chalmers did not.<sup>7</sup>

They point out that the legacy of the cervical cancer inquiry is not as Raffle and Gray claim “a climate of mistrust between patients and health professionals” but change that has “led to informed consent enshrined in law, ethical oversight of research, and a cervical screening programme that has reduced the incidence of cervical cancer by over 50 percent.” They say that “by and large health providers and their colleges embraced the need for change.”<sup>7</sup>

Dr Ron Jones describes how he was “a young colleague of Herbert Green... I have first-hand experience, sadly, of the harms caused by Green withholding treatment. I was also a co-author of the paper that initially exposed the truth about Green’s experiment (this paper is completely misunderstood by Chalmers, as his thesis is based on conservative treatment and Green’s experiment was based on no treatment).”<sup>8</sup>

Ron Jones goes on to point out an uncomfortable truth: “The introduction of screening was delayed in New Zealand because of Green’s implacable opposition. If as had been suggested in 1959 by Dr George Weid, a national screening program had been introduced, rather than in 1991, about 3,200 New Zealand women would have been prevented developing cervical cancer.”<sup>8</sup>

Emeritus Professor Charlotte Paul writes that Raffle and Gray “rely uncritically on Professor Linda Bryder’s *A History of the ‘Unfortunate Experiment’ at National Women’s Hospital*, 2009.”<sup>9</sup> She goes on to say that “scholarly integrity insists that Raffle and Gray should have evaluated the detailed critiques of Bryder’s work before deciding whether to rely



on her,” specifically recommending *The Cartwright Papers* (ed. J Manning, 2009) and *Doctors in Denial* (2017) by Ron Jones.<sup>9</sup>

Prof Paul writes that she corresponded with Chalmers some ten years prior, writing “This is not just an academic dispute. I care about the harms that patients suffered. I care about medicine owning up to its mistakes. I reckon people need to be brave and speak out in this circumstance. If this continues to bring denigration on me, so be it. Matters more important than my reputation are at stake.”<sup>9</sup>

This is precisely what it is all about — the harms that patients suffer, accepting and owning up to mistakes, and speaking out to ensure that patients and their rights are protected and that lessons are learned. This a large part of what drives the Auckland Women’s Health Council and many other NGOs. Matters more important than reputations are at stake.

## In Conclusion

Scientific debate always continues — medical science and understanding is not fixed and immutable, it is always changing. For the AWHC the main issue is one of informed consent and patient rights. The right to informed consent should remain a constant and unassailable truth. Sandra Coney and Phillida Bunkle’s article in *Metro* magazine led directly to the Cartwright Inquiry, and from Judge Silvia Cartwright’s recommendations the Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 was enacted in New Zealand.

Regular readers of this newsletter will know that those rights are not always adequately applied; breaches of those rights are regularly the subject of complaints to the Health and Disability Commissioner, and it seems that some health practitioners and organisations providing health services feel that rights of informed consent can be dispensed with. But no-one in the health sector can justifiably claim that they do not know that patients have these rights, or that the onus is on practitioners to obtain fully informed consent from patients. This is the legacy of the Cartwright Inquiry and possibly the only upside to the suffering of the women who were involved in Herbert Green’s research without their knowledge or consent.

For the many younger New Zealanders who did not live through the Cartwright Inquiry, or who were too young to take an interest in it, the constant debate and rehashing of the facts and opinions in this matter may be confusing and off-putting. The AWHC suggests that people wanting to know more start with Sandra Coney and Phillida Bunkle’s original *Metro* article (on the AWHC website) then read:

1. *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women’s Hospital and into Other Related Matters* accessible at <https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/legislation/cervical-screening-inquiry-0>
2. *The Cartwright Papers: Essays on the Cervical Cancer Inquiry, 1987–1988*, edited by Joanna Manning, Published in 2010 by Bridget Williams Books (out of print, but can be borrowed through Auckland Libraries, or purchased from Hard to Find Books).
3. *Doctors in Denial: the forgotten women in the ‘unfortunate experiment’* by Ron Jones Published in 2017 by Otago University Press, and available from Fishpond.

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# Health News Briefs

## ***Johnson & Johnson loses court appeal over surgical mesh injuries***

Finally, more than 10,000 Australian women will get monetary compensation, in total in the hundreds of millions of dollars, after Johnson & Johnson's appeal against a landmark 2019 ruling failed in early March 2021.<sup>1</sup>

In 2019, an Australian federal court found "Johnson & Johnson Group firms acted negligently and concealed the true extent of complications from the pelvic implants."

Johnson & Johnson appealed the judgment, claiming there were numerous legal errors, but on the 5<sup>th</sup> of March this year the Federal court dismissed the appeal. In her original judgement in 2019, Justice Anna Katzmann found the "Instructions for Use" handed to surgeons minimised harm and exaggerated the benefits of the devices.

While this is a moral victory for all women who have suffered devastating and life-changing injuries from the surgical mesh they had implanted on the understanding that it would fix their problems with stress urinary incontinence or pelvic organ prolapse, it does little to help the hundreds of New Zealand women still suffering.

Under our no-fault ACC system, New Zealand patients can't sue or be part of a class action against any mesh manufacturer.

This 'injustice' was a common feature of the stories of mesh survivors who took part in the 2019 surgical mesh restorative justice process.

"One patient described ACC's default response as 'deny, defer, defend'. Many were frustrated and angry that ACC frequently denied treatment injury claims, suggesting, 'In the US [the manufacturers] have paid millions, but I can't sue because of the existence of ACC' ".<sup>2</sup>

The restorative justice report found that "Numerous people wanted mesh injured New Zealanders to have the opportunity to sue the manufacturers of mesh products:

"We, the injured, hear all the time about massive pay-outs that people overseas have received, and yet

we have to fight our way through ACC's bullshit, and hope for a lump sum, which is a pittance in comparison. My life as it was is over, I can't get it back. All I can do is try and make the most of what my body is now able to do, and money would most definitely help with this."

ACC have acknowledged the harm that patients' experiences dealing with and being declined by ACC

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— Hearing and Responding to the Stories of Survivors of Surgical Mesh, Restorative Justice report<sup>2</sup>

has caused, and they have committed to looking back through declined surgical mesh claims to check those past cover decisions are consistent with the latest understanding of mesh injuries.<sup>3</sup>

AWHC are thrilled that the New Zealanders who have had mesh injury claims declined will now have an opportunity to have their claims reassessed. If you had a claim declined before 28 October 2020 get in touch with ACC — more information about the process, how the reassessment will work and how those seeking reassessment will be supported, is on their website at <https://www.acc.co.nz/surgical-mesh/>

1. Johnson & Johnson loses court appeal over pelvic mesh negligence, *The Guardian*, 5 March 2021 accessed at <https://www.theguardian.com/australia-news/2021/mar/05/johnson-johnson-loses-court-appeal-over-pelvic-mesh-negligence>
2. Wailing J, Marshall C & Wilkinson J, 2019: *Hearing and responding to the stories of survivors of surgical mesh: Ngā kōrero a ngā mōrehu – he urupare*, A report for the Ministry of Health. Wellington, New Zealand: The Diana Unwin Chair in Restorative Justice, Victoria University of Wellington.
3. ACC: Reassessing declined surgical mesh claims, accessible at <https://www.acc.co.nz/surgical-mesh/>

## ***Miscarriage Bereavement Bill***

That a parent has not held their child in their arms, named their baby, watched them sleep or cry or smile, does not lessen the grief for those who lose a child before birth. Whether it is in the first few weeks – the first trimester, or later in pregnancy when a parent has seen them on a scan and felt them kick; or if their child is still born; whether it is a parent's first pregnancy or last, grief still accompanies the loss of an unborn child.

Yet few speak about it, albeit there are now wider conversations about miscarriage and still birth than a few years ago. It has been such a hidden loss for so long that many women have felt that they “were the only ones” or have felt obliged to keep their grief private and under wraps.

This author has known many women who have lost a very much loved and wanted baby: many in the first trimester; one a longed-for IVF baby; one a baby who died *in utero* at six months; one woman who lost two babies to serious genetic conditions that were “incompatible with life”; numerous women suffering multiple miscarriages for no known reason. Like many women, I too miscarried — both my first and second. At the time though, I was alone, without my partner at my side when I was told that my first baby no longer had a heartbeat. This amplified the grief.

Now the grief that parents in New Zealand feel at the loss of a baby in pregnancy, or because of stillbirth, is being acknowledged. In a wonderful show of compassion, unity and understanding of what it is to lose an unborn baby, Parliament has unanimously passed legislation giving mothers and their partners three days of bereavement leave following a miscarriage or stillbirth. The legislation also applies to parents planning to have a child through adoption or surrogacy.

The members bill was put forward by Labour MP Ginny Andersen and she said “the bill will give women and their partners time to come to terms with their loss without having to tap into sick leave. Because their grief is not a sickness, it is a loss. And loss takes time,” and she acknowledged MPs across the House for their unanimous support.

“The passing of this bill shows that once again New Zealand is leading the way for progressive and compassionate legislation, becoming only the second country in the world to provide leave for miscarriage and stillbirth,” Ms Andersen said.

## Sources

Holidays (Bereavement Leave for Miscarriage) Amendment Bill (No 2) accessed at <https://www.legislation.govt.nz/bill/member/2019/0159/latest/LMS220706.html>

Employment New Zealand 2021: Bereavement leave to cover miscarriage, stillbirth accessed at <https://www.employment.govt.nz/about/news-and-updates/bereavement-leave-to-cover-miscarriage-stillbirth/>

TVNZ, 2021: Parliament unanimously passes bereavement leave for miscarriages, stillbirths — second in the world to do so, TVNZ accessed at <https://www.tvnz.co.nz/one-news/new-zealand/parliament-unanimously-passes-bereavement-leave-miscarriages-stillbirths-second-in-world-do-so>

## Possible New Endometriosis Treatment

As many as ten percent of women suffer from endometriosis, a crippling painful condition in which tissue similar to the endometrium or lining of the uterus grows outside the uterus. Symptoms include painful periods, painful ovulation, pain during or after sex, heavy bleeding, chronic pelvic pain, fatigue, and infertility. It can start as early as a girls first period and menopause doesn't necessarily mean an end to the condition. Treatment – with greater or lesser degrees of success – can only manage the symptoms, not cure the condition, and many women undergo multiple surgeries.

Now researchers in Oregon (US) have developed a potential nanotechnology-based treatment that may alleviate the pain and fertility problems associated with endometriosis. They used tiny – less than 100 nanometers in size – polymeric materials packed with a dye that can generate both a fluorescence signal and cell-killing heat under near-infrared light.

Researcher Dr Olena Taratula, said “we developed and evaluated the photo-responsive nanoagent to detect and eliminate unwanted endometrial tissue with photothermal ablation.”

That means injecting the dye-loaded nanoparticles into the body, where they fluoresce to show where the lesions are, and also kill them with heat because the particles increase to 53°C upon exposure to near-infrared light.

“The challenge has been to find the right type of nanoparticles,” Dr Taratula said. “Ones that can predominantly accumulate in endometriotic lesions without toxic effect on the body, while preserving their imaging and heating properties.”

“The heat is produced under near-infrared laser light that is harmless to tissue without the presence of the nanoparticles. The generated heat eradicates the endometrial lesions completely within a day or two. Dr. Slayden and I built this team years ago to help surgeons to better visualize and treat endometriosis lesions, and we're getting close.”

While this research provides hope to endometriosis sufferers it could be some time before it progresses to a viable treatment. At this point the treatment has only been tested on primates (macaque monkeys) and has yet to be developed for human trials.

There is no known cause for endometriosis, and as many as one in ten women suffer from the condition. While ongoing research to find a cure, or at least better treatment, is laudable, given that so many women have the condition it would seem more useful – and



in the long term cost effective – to undertake more research to identify the cause and find ways in which to prevent it. In addition, a change in attitude towards women presenting with symptoms of endometriosis would alleviate some of the suffering women with this condition endure. Doctors need to show more empathy and recognition of this condition and help reduce the delay in diagnosis.

## Sources

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## Abortion Without Harassment

On the 18<sup>th</sup> of March 2020, the Abortion Legislation Act passed with a majority vote of 68 to 51. However, a week earlier during the Committee of the Whole House stage of debating, the proposed legislation, Act MP David Seymour proposed an amendment to scrap safe zones from the Act. In an apparent voting mix up the amendment was passed, and this part of the proposed bill failed to make it into the legislation.<sup>1</sup>

Now, Labour MP Louisa Wall has introduced a member's bill<sup>2</sup> to provide a regulation-making power to set up safe areas around specific abortion facilities on a case-by-case basis. This bill if passed will reintroduce measures to safe-guard a pregnant person's right to attend a clinic for abortion with some measure of safety and freedom from harassment.

AWHC strongly believes that those accessing abortion services must be free from intimidation. Terminating a pregnancy may involve considerable emotional distress and harassment and intimidation when accessing abortion services adds unnecessary distress and judgement to the situation.

No other health services attract the same overt judgement and objection as abortion services. As abortion services are health care, they should be afforded the same common decency and privacy as other health care services afford. When making submissions on the Abortion Legislation Act we argued that "To ensure privacy is given to people accessing abortion services we suggest the safe space be extended from 150 meters to 500 meters and for this to be a mandatory requirement around all abortion service facilities."<sup>3</sup>

We also asked that the legislation also include the partners and supporters of those seeking abortion

services who may be accompanying them in the "safe zone" provisions.

Consequently, it was very disappointing to find that any and all provisions for "safe zones" had been removed from the final form of the Act, and we are pleased that this new bill will go some way to restoring the intent of the original proposed legislation.

However, the Contraception, Sterilisation, and Abortion (Safe Areas) Amendment Bill does not propose to implement safe zones for all abortion facilities. The bill states that:

"The decision to make regulations creating a safe area would be made on the recommendation of the Minister of Health, in consultation with the Minister of Justice. The specific size and exact location of the safe area would be determined on a case-by-case basis, as appropriate for the individual facility's circumstances. The details would be set out in the regulations made for specific premises."

Terry Bellamak, President of ALRANZ points out that "The process in section 13C of the bill is truly ridiculous – to create one safe area you need an order in council on the recommendation of Cabinet's two busiest ministers in consultation with each other."<sup>4</sup>

AWHC would like to see "safe zones" implemented for all abortion facilities as a matter of course without having to undertake the laborious process set out in the proposed bill. No person should be subjected to harassment while seeking health care services of any description, and provisions for freedom of speech should not override an individual's right to access services free from intimidation.

Submissions on the proposed bill can be made up until 11.59pm on Wednesday, 28 April 2021. We encourage all interested people to make a submission, and this can be done online at [https://www.parliament.nz/en/pb/sc/make-a-submission/document/53SCHE\\_SCF\\_BILL\\_99649/contraception-sterilisation-and-abortion-safe-areas](https://www.parliament.nz/en/pb/sc/make-a-submission/document/53SCHE_SCF_BILL_99649/contraception-sterilisation-and-abortion-safe-areas)

## Sources:

1. Wade A, 2020: Voting mix-up sees abortion safe-zones axed and MPs 'gutted', *New Zealand Herald*, 11 March 2020.
2. Contraception, Sterilisation, and Abortion (Safe Areas) Amendment Bill accessed at <https://legislation.govt.nz/bill/member/2020/0310/latest/whole.html#LMS378598>
3. AWHC, 2019: *Abortion Law Reform Submission September 2019*, accessible at <https://www.womenshealthcouncil.org.nz/Features/AWHC+Submissions/Abortion+Law+Reform+Submission+September+2019.html>
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