



NEWSLETTER

February/March • 2022

a voice for women's health

International Women's Day

Celebrating our wāhine toa...



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AWHC

Annual General Meeting

The Auckland's Women's Health Council AGM will be held at **10.00 am on Wednesday the 4th of May 2022** via Zoom.

If you are interested in attending the AGM please RSVP by email to receive further details and a Zoom link.

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INTERNATIONAL WOMEN'S DAY

#BreakTheBias

Celebrating our Wāhine Toa

Tuesday the 8th of March was International Women's Day; a day that aims to focus global attention on the state of women when it comes to gender equality, bias, stereotypes and discrimination. Inequity, bias and discrimination affect many women when it comes to their health and well-being and, sadly, in their interaction with health services. In many cases the inequity, bias and discrimination are embedded in the way in which our health practitioners are trained, the legislation and regulation governing our health agencies and entities, and in health policy at the highest level. Inequity, bias and discrimination against women in health has been around for centuries and, despite advances in recent decades, we still have a long way to go.

Regular readers of this newsletter will be well aware of the significant inequities, biases and discrimination in women's health that we write about.

In. Every. Single. Edition.

This year, to celebrate International Women's Day we celebrate New Zealand women who have not only had a close association with, or made a huge impact on, Auckland Women's Health Council, but who have made a significant contribution to addressing the issues that impact on women's health and well-being in this country.

Every day for a week we posted about these women on our Facebook page. Seven days, eleven women. There are tens if not hundreds of New Zealand women/wāhine that have done and continue to do amazing work to address the inequities, disparities and discrimination that women face in our health system, in medical research, in their interaction with health and disability services providers, and at a policy and governance level. There is not time and space to adequately acknowledge all the wāhine toa working in this space. We would like you to accept that our small celebration of these eleven women is a de facto celebration of all the other women giving so much of themselves to improve women's health and wellbeing.

Sandra Coney and Phillida Bunkle

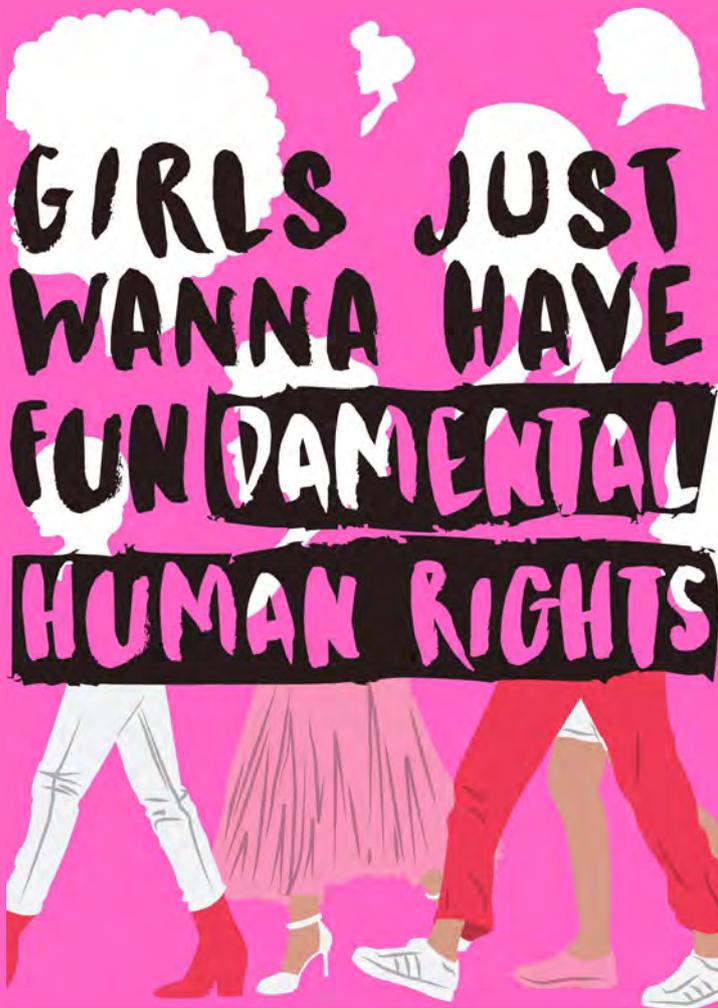
Sandra Coney and Phillida Bunkle kicked off a health revolution in Aotearoa New Zealand with their 1987 *Metro* article, "An Unfortunate Experiment at National Women's". Their research was triggered by the 1984 paper by Drs Bill McIndoe, Malcolm "Jock" McClean and Ron Jones, and Peter Mullins, published in the journal *Obstetrics and Gynecology*, which discussed Herbert Green's work at National Women's Hospital on women with abnormal cervical cytology. The paper suggested that some patients had been diagnosed with cervical cancer but not treated.

Reaction to the *Metro* magazine article was public outrage and within ten days, then Minister of Health, Michael Bassett, established a Committee of Inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital, led by Judge Silvia Cartwright. It subsequently became known as the Cartwright Inquiry and Sandra Coney was one of a large number of witnesses to provide testimony.

Sandra was a founding member of the Auckland Women's Health Council, and both Sandra and Phillida are members of the Cartwright Collective, a group committed to monitoring the implementation of the 1988 Cartwright Inquiry Report Recommendations.

Sandra Coney and Phillida Bunkle put both informed consent and women's health issues very firmly on the agenda and, at least for a time, at the forefront





International Women’s Day (IWD) was first celebrated more than 100 years ago in 1911, after having been proposed by Clara Zetkin, a communist activist and advocate for women’s rights, at the 1910 International Socialist Women’s Conference; the 100 women from 17 countries at the conferences unanimously agreed.

The seeds for the IWD had been planted in 1908 by a 15,000 strong march of women through New York, demanding shorter working hours, better pay and the right to vote. The following year the first National Woman’s Day (NWD) was observed across the United States on the 28th of February.

International Women’s Day was first celebrated in 1911 in Austria, Denmark, Switzerland and Germany, and more than a million people turned out to rallies in Europe. For most of the 20th century IWD was acknowledged at a grass roots level; it wasn’t until 1975 – International Women’s Year – that the United Nations adopted International Women’s Day on the 8th of March.

In 2001, the internationalwomensday.com platform was launched with the specific purpose of re-energising the day – a focus that continues to this day – celebrating and making visible the achievements of women while continuing the call for accelerating gender parity. This year the theme is ‘break the bias’.

Imagine a gender equal world. A world free of bias, stereotypes and discrimination. A world that's diverse, equitable, and inclusive. A world where difference is valued and celebrated.

— internationalwomensday.com



Sandra Coney and Phillida Bunkle (far left) together with members of the Auckland Women’s Health Council visit (5 August 2018) the memorial plaque that bears witness to the bravery and dedication of Dr Bill McIndoe, the cytologist and colposcopist at National Women’s Hospital from 1963 to 1983, and Dr Malcolm McLean, the pathologist from 1961 to 1988.

of the Aotearoa New Zealand consciousness. The impact of their article cannot be overstated; it represents a paradigm shift in attitudes to medical and research ethics, and patient rights. Sadly, for all their work, and the work of many others in the area of patient rights and the right of patients to make truly informed decisions, infringement of informed consent rights is one of the most complained about issues in interactions with health and disability services providers.* Today, at AWHC we regularly address breaches of informed consent rights; from DHBs and teaching hospitals failing to understand their obligations to obtain informed consent from patients being observed or treated by doctors in training; to individuals who have been inadequately informed of the risks of the health care and treatment being recommended to them.

* Informed consent is one of the most common complaint issue categories in complaints to the Health & Disability Commissioner. In the year to June 2021, 19% of complaints included informed consent issues; in the 2019-20 year 14%; in 2018-19 15%; in 2017-18 15%. Source: HDC annual reports)



Dame Silvia Cartwright speaking at 'The Cartwright Legacy at 25 Years', 2013, hosted by the Cartwright Collective and sponsored by the Auckland Women's Health Council and the Cancer Society.

Dame Silvia Cartwright PCNZM DBE QSO DStJ

Dame (formerly Judge) Silvia Cartwright has not had direct involvement with the Auckland Women's Health Council, but the Cartwright Inquiry, the report and Dame Silvia's recommendations in the report, had a formative influence on the early years of the AWHC and left an indelible mark on the health landscape in Aotearoa New Zealand.

While the Cartwright Inquiry and subsequent report made some astonishing revelations about the abuse of medical power, the horrendous imbalance in the power relationship between patients – particularly women patients – and doctors, and the relative absence of research ethics, it was in her recommendations that Dame Silvia had the greatest impact changing the way that health services were delivered for all New Zealanders. A direct consequence of her recommendations was the establishment of the Health and Disability Commissioner followed by the development of the Code of Health and Disability Services Consumers' Rights, enshrining in law, among other things, the right of patients to be fully informed and provide informed consent to treatment, and participation in medical research.

Dame Silvia's recommendations also led to:

- the establishment of a patient advocate role at National Women's Hospital;
- the establishment of medical ethics committees (Health and Disability Ethics Committees) which must review and approve all medical and health research in Aotearoa New Zealand before it can proceed;
- the design and implementation of the National Cervical Screening Programme.

Beyond the Inquiry into the allegations concerning the treatment of cervical cancer at National Women's Hospital that bears her name, Dame Silvia Cartwright is wonderful woman to celebrate for International Women's Day. She was Aotearoa New Zealand's first female Chief District Court Judge, the first woman to be appointed to the High Court and our second female Governor General. She served on the Committee on the Elimination of Discrimination against Women and played a major role in the drafting of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women. In 1989, she was appointed a Dame Commander of the Order of the British Empire, for services to women, and in 2001 was made a Principal Companion of the New Zealand Order of Merit, an honour that, together with Knights and Dames Grand Companion, is limited to 30 living people.

Judi Strid MNZM

Judi was a truly remarkable woman, a leader and one of the most effective change agents in the maternity sector in Aotearoa New Zealand during the 1980s and 1990s. Together with Lynda Williams, Judi joined and/or established consumer groups and worked on numerous issues of concern in the maternity sector. Judi was an inspiring and hard-working member of the Home Birth movement, Save the Midwives and Maternity Action, as well as many other groups.

In 1986 she helped form, and then led, the Direct-Entry Midwifery Task Force, the aim of which was to see the establishment of a direct-entry midwifery programme in Aotearoa New Zealand. Over the next four years Judi led this hugely successful campaign. As co-ordinator of the Task Force, Judi inspired and motivated other members with her passion and enthusiasm for the cause. The passing of the Nurses Amendment Act in August 1990 was an overwhelming victory for all those involved.



Judi with Marie Bismark at the "The Cartwright Legacy at 25 Years" conference to mark the 25th anniversary of the release of the Cartwright Report

Judi was a founding member of the AWHC and was our first paid co-ordinator. She worked tirelessly for the Council, organising fundraising book fairs, writing grant applications, and attending hundreds of meetings, including those of the newly formed Auckland Area Health Board. She also played a major role in the formation of the Federation of Women's Health Councils in 1990 and subsequently worked in a volunteer role as the first convenor of the Federation for several years.

Judi was also involved in the hui on maternity services consumer representation that led to the formation of the Maternity Services Consumer Council in 1990.

After resigning from AWHC and MSCC, Judi went on to set up the Women's Health Information Unit at National Women's Hospital, where she became renowned for her commitment to ensuring women (and health professionals) had access to the latest evidence-based information on a wide range of women's health issues. She also became a member of the Women's Health Action Trust, a position she held until 2001.

In 2004, Judi was appointed Director of Advocacy at the office of the Health and Disability Commissioner, a position she held until November 2014. She was a tireless champion of health and disability consumer advocacy and of the Code of Rights in her role as Director. Judi also served as the HDC representative on the National Quality Improvement Committee, where she championed the consumer voice.

In 2005, Judi was made a Member of the New Zealand Order of Merit (MNZM) for her services to women's health. Among her many achievements, her lasting legacy is the right of Aotearoa New Zealand women to choose their own midwives to care for them during pregnancy, a right the value of which is probably underestimated today by many women.

Judi died in 2015.

Lynda Williams MNZM

Lynda Williams' feminist principles and history of advocating and lobbying for women's rights regarding birthing choices called her to be one of the founding members of AWHC. She was involved in several of the working groups set up following the release of the Cartwright Report and was appointed as the first patient advocate at National Women's Hospital, fulfilling one of the key recommendations from the inquiry.

In 1995, Lynda took up the role of AWHC's co-ordinator. It was through all the qualities that she possessed – her persistence, courage and commit-

ment to social justice – that AWHC was and is what it is. Her scholarship and rigour were evident in the monthly Newsletter she produced; that the Newsletter was subscribed to by academics and politicians shows how highly regarded and useful her writing was. She was also sought after by both national and international journalists for the AWHC's views on health issues.

In addition to Lynda's 29-year involvement with the AWHC, she founded the Auckland Caesarean Support Group in 1984, set up and co-ordinated the Childbirth Education Association of Auckland over a period of seven years and supervised childbirth educators completing their training, and was co-ordinator of the Maternity Services Consumer Council for more than 20 years. Lynda also represented consumer concerns on several ethics' committees, including the Auckland Hospital Ethics Committee and the Green Lane Hospital Ethics Committee. For a time, Lynda was also an elected member of the Auckland District Health Board.

Once described by former Health and Disability Commissioner, Professor Ron Paterson, "as a vigorous activist who never hesitated in keeping the medical profession and health agencies on their toes", Lynda herself acknowledged that as a women's health activist she was a "pain in the butt to the health system." One of her final victories was that, after several years of persistent lobbying of then HDC, Anthony Hill, he finally issued a consultation



Lynda Williams with Governor General, Dame Patsy Reddy, on the occasion of her investiture as a Member of the New Zealand Order of Merit.

document seeking submissions on the ethics of involving patients unable to provide consent to participate, in medical research. Lynda made her last submission on this consultation –vehemently opposing the continued involvement of incapacitated patients in medical research – only weeks before she died in July 2017.

Lynda was made a Member of the New Zealand Order of Merit in the 2017 New Year Honours for her services to women's health. Lynda continues to inspire many women's health activists and advocates. She would be disappointed that there is still so much work to do, and that many of the issues she was raising awareness of and actively fighting to change over thirty-five years, are still adversely impacting on women's health and well-being; but she would be proud that so many women are not taking the status quo lying down and are still fighting for change.

Joan Donley OBE RM MHS (Honorary)

Joan Donley was a fearless champion of women's rights, an internationally renowned midwife and author, and a much loved and respected Auckland Women's Health Council member. She was a tireless and tenacious advocate and an inspiration to all who worked alongside her. She was unstintingly generous in sharing her knowledge and insights and was an example to us all. Her sense of humour and irreverence always kept us going when the going got



Joan Donley on her 80th birthday.

rough. Her legacy lives on in the babies she helped bring into the world, in the organisations she helped found and those she supported, and in her books advocating for normal pregnancy and birth.

Joan was an early member of the Auckland Women's Health Council. She was actively involved on the Executive Committee and was best known for her passion for birthing issues; she ensured that our submissions on all things maternity were based on quality research. One example of this was in AWHC's oral submission to the Health Select Committee on maternity issues in which she gave a cost breakdown of a caesarean birth compared to that of a vaginal birth. The Health Select committee members were very taken by this canny economic pitch and there was a good degree of engagement, which is not always the case.

Joan was a staunch feminist, committed to women not being exploited in the interests of others. She viewed having a baby at home as a 'feminist and a political act' in which 'women rebelled against the technological takeover of their bodies' by male doctors and hospital nurses. She believed in equity and justice, and recognised the impact of poverty and the need for this to be addressed. Related to this was Joan's holistic view of health and the importance of good nutrition.

Joan aimed for women to become empowered and enabled to choose for themselves. She provided them with broad information. It is these values and beliefs that are some of the legacy that Joan has left AWHC and which still drive our work.

However, Joan leaves a legacy far beyond AWHC. In 1978 she formed the Auckland Home Birth Association, a lobby group for domiciliary midwives, and she was a founding member of the New Zealand Domiciliary Midwives Society, established in 1981. She was integral in bringing about midwifery autonomy and it was because of her ability to bring together women and midwives that midwifery autonomy in 1990 came about with the Nurses Amendment Act. Her oft quoted slogan for this unique partnership was "Women need midwives need women". Another oft quoted slogan was "Pizzas are delivered. Women give birth".

Joan was also a founding member of the College of Midwives. In 2001, NZCOM established the Joan Donley Midwifery Research Collaboration (JDMRC) – the evidence arm of the College that provides the framework and secretarial support for the College's research programme. Set up in honour of Joan and her commitment to an evidence-based midwifery profession, its core purpose is to promote the development of midwifery research, and thereby the

provision of evidence for practice, in Aotearoa New Zealand's unique maternity service context. NZCOM also holds the biennial Joan Donley Midwifery Research Forum.

Her book *Save the Midwives* is still read, and her *Compendium for Healthy Pregnancy and a Normal Birth* is not only still available, but highly sought after and prized by women wanting to take a holistic approach to their pregnancies and the births of their babies.

Joan Donley was made an OBE in 1990 for services to midwifery, and was awarded both the New Zealand 1990 Commemoration Medal and the New Zealand Suffrage Centennial Medal 1993. In 1997 she was awarded an honorary Master's degree in midwifery from the Auckland Institute of Technology.

Jo Fitzpatrick

Jo's association with the Auckland Women's Health Council goes back to the days, when as Director of Women's Health Action, she provided a place for AWHC to hold its meetings; she joined the AWHC committee in 2004.

Jo was an astute judge of the political processes/dynamics that occurred at the various meetings or within the health system. She had integrity and stood firm on issues and in her values. She brought humour and scholarship to the table. Her ability to interpret information quickly and provide direction to us was invaluable to the AWHC.

She was a very principled woman and lived her life accordingly; she investigated issues fully, was always ethical and she never put herself before put the issue or the cause. She did things with a lot of grace and intelligence; she was warm, gentle and kind; and



Jo Fitzpatrick.

above all, Jo stood up for social justice and fairness and equal opportunities.

Jo was a true watchdog on behalf of consumers, and voiced her opinions on issues ranging from direct to consumer advertising of drugs, the high cost of medicines and cosmetic surgery, to doctors' professional standards. She was actively involved as a consumer representative in high policy-level working groups for many key health system-planning activities. She brought her formidable consumer lens to a wide range of issues including:

- organ donation, and assisted reproductive technology (ECART);
- internet connectivity across the health sector, including electronic health records and patient portal developments, being on the Consumer Panel of the National IT Board;
- chairing the NGO-Ministry of Health Working Party on the Regional Shared Care Project Consumer Empowerment Group;
- being on the Board of Diabetes NZ and bringing her personal experience with diabetes and her professional expertise in Governance to the organisation.

She had a strong commitment to the right to health and human rights for all people, and to protecting and promoting NGO participation in the health sector; a belief that inequality and discrimination are addressed by education and empowerment; the ability and stamina to achieve challenging goals in challenging environments.

The value of her wider contributions, especially to women's health, were reflected in three NGOs in particular; as a long standing and highly valued member of Auckland Women's Health Council committee, as director of Women's Health Action, and as an integral member of the Cartwright Collective.

In her plenary address at a seminar on the Legacy of Cartwright marking the 25th anniversary of the Cartwright Report, Jo summed up progress in the consumer experience since the Cartwright Inquiry by saying loud and clearly:

"There has been very little ceding of power to consumers in health in the last 25 years. We need more consumer advocates in many more places in health. Consumer representation is not a competitive sport, we can all bring our experiences and advocacy to the role".

The Women of Mesh Down Under

Charlotte Korte, Carmel Berry, Patricia Sullivan and Renate Schütte have all suffered harm from surgical

mesh. They could have sat back and just focused on their own health and recovery, but instead they have been fighting for years to ensure that other women don't have to suffer the same harm from mesh that they have suffered, and that New Zealanders have a responsive and effective health and disability complaints system.

Charlotte, Carmel and Patricia co-founded Mesh Down Under, and in 2018, Charlotte won a Woman of Influence award for her work campaigning for the cessation of harmful mesh procedures. Those who nominated Charlotte wanted to nominate Carmel and Patricia as well, but could only nominate a single woman. Charlotte was adamant that the award was for all three, even if only she would be named.

Without these women it is unlikely that much would have changed on the surgical mesh scene in Aotearoa New Zealand. They have not just supported and advocated for other mesh injured New Zealanders. They co-presented a petition to Parliament; spoke at the Australian Senate inquiry into surgical mesh; criticised politicians and health officials for failing to act decisively; and have worked with surgeons to improve patient information materials.

Their dogged advocacy and lobbying forced state health entities to face up to the damage caused to more than 1000 New Zealanders by the use of surgical mesh, including being the catalyst for a Medsafe report on mesh harm (finding 1325 formal reports of harm to June 2019), and an ACC report on surgical mesh claims (771 accepted claims to June 2018). In addition, they have consistently campaigned for a surgical mesh registry, which resulted in a Deloitte cost benefit analysis, which found in favour of a mesh registry by 3.1 to 1.

These years of unpaid advocacy work by Charlotte, Carmel and Patricia ultimately led to the 2019 Restorative Justice process for those harmed by

mesh, through which more than 600 people told their stories. As a result of that process, in 2020 ACC agreed to review all mesh injury claims back to 2005.

On the other side of the mesh debacle is Renate Schütte, whose own experience with recovering from significant mesh injury led her to lodge a complaint with the Health and Disability Commissioner; her complaint of serious harm and infringement of her rights received a "no further action" decision. The outcome added insult to injury and her disillusionment with our complaints process saw her petition Parliament to make changes to the Health and Disability Commissioner Act to allow the right to appeal HDC decisions. Renate, with support from Charlotte, law professor Jo Manning and Sue Claridge of AWHC, spent months working on written and oral submissions and lobbying the Health Select Committee to open up submissions to other interested parties, lobbying the Government to give New Zealanders a more effective and responsive, fairer and more just health complaints system.

These women don't see themselves as remarkable or extraordinary, yet they are; they have achieved extraordinary things in their determination to improve the lives of other New Zealanders and to ensure no more people suffer as they and countless others have. They have seen and experienced injustice and spoken out. They are the consumer voice and they have shown what ordinary women can achieve by speaking out about the issues in our health system that so desperately need to change.

All these women stepped up to address inequity, bias and discrimination suffered by women in our health system. As individuals and collectively they have made a huge difference in the lives of other ordinary women, as have many, many others before them.

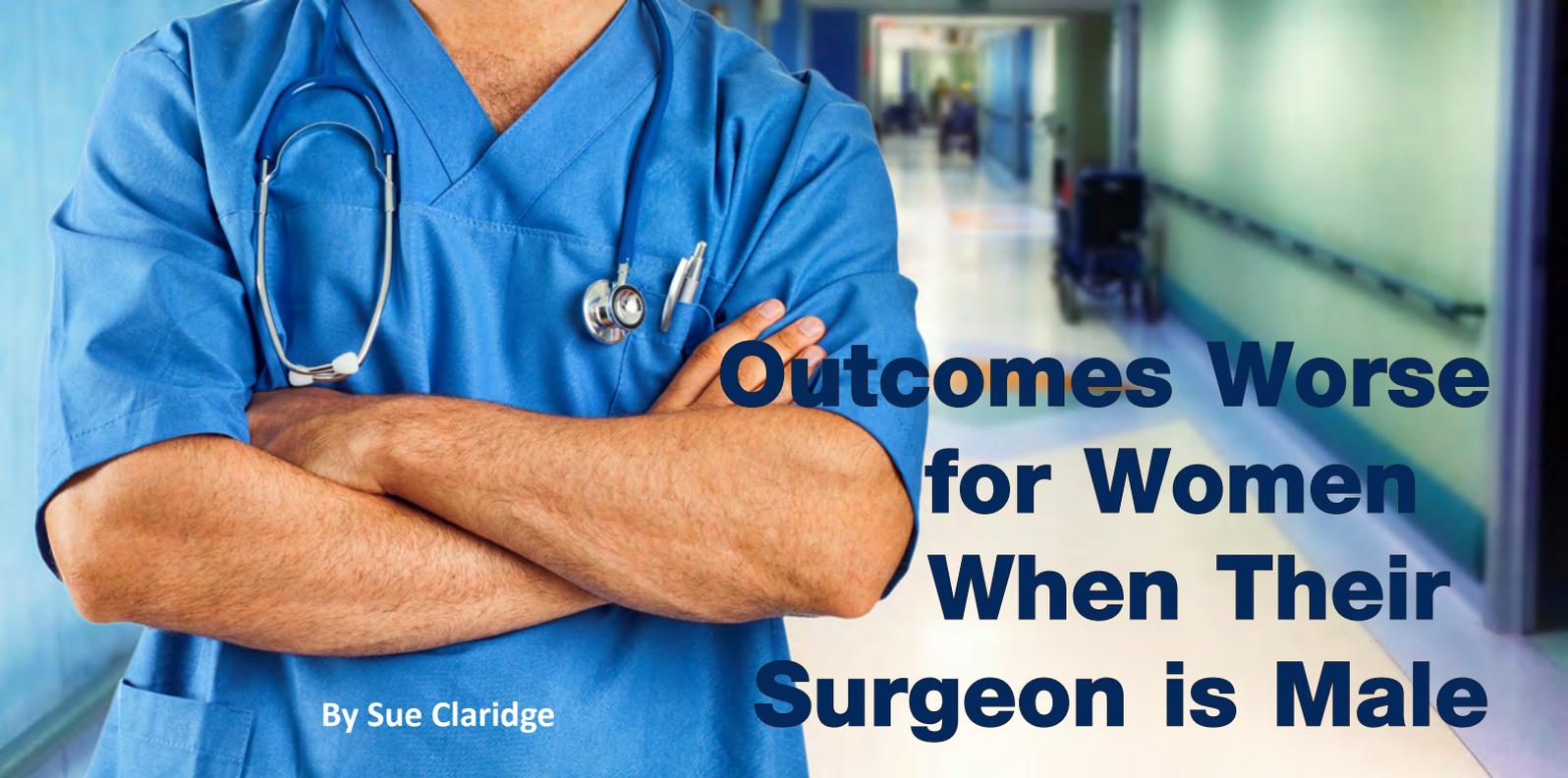
Amazing women; wāhine toa... we salute you and celebrate what you have done for us.



Charlotte Korte, Carmel Berry and Patricia Sullivan.



Renate Schütte.



Outcomes Worse for Women When Their Surgeon is Male

By Sue Claridge

Women facing surgery may want to think carefully about who their surgeon is and perhaps ask questions about his prior post-surgical outcomes for female patients.

Research from Canada, published in *JAMA Surgery* in 2022,¹ found that women patients with male surgeons suffered significantly worse outcomes than women patients with female surgeons. The same disparity was *NOT* seen in male patients treated by female surgeons compared with male patients treated by male surgeons.

Researcher Dr Angela Jerath and colleagues write that “In primary care, sex or gender discordance between patients and physicians (particularly among male physicians and female patients) is associated with worse rapport, lower certainty of diagnosis, lower likelihood of assessing patient’s conditions as being of high severity, concerns of a hidden agenda, and disagreements regarding advice provided.”¹

Jerath and her colleagues hypothesised that sex discordance between surgeons and patients (i.e. female patient and male surgeon, or male patient and female surgeon) may contribute to differences in postoperative outcomes, with worse outcomes in female patients treated by male surgeons.

They investigated post-surgical outcomes among 1,320,108 patients treated by 2937 surgeons, including 717,548 sex discordant surgeries – 667,279 male surgeon and female patient surgeries, and 50,269 female surgeon and male patient surgeries. Twenty-one types of surgery were analysed including cardiothoracic, orthopaedic, thoracic, plastic, vascular, neurosurgery, urology, otolaryngology

and general surgery. In addition, the researchers controlled for patient age and comorbidity, complexity of the surgery, elective versus emergency surgery, and surgeon characteristics (volume of surgeries, years in practice, age, and hospital status – academic vs community).¹ In their analysis the researchers excluded sex-specific procedures (e.g. hysterectomies).

Overall, they found that 189,390 patients (14.9%) experienced an adverse postoperative outcome: 22,931 (1.7%) died, 88,132 (6.7%) were readmitted, and 114,421 (8.7%) had significant complications in the 30-days following surgery.¹

Female patients were 15% more likely to experience adverse outcomes following common surgical procedures when treated by a male rather than a female surgeon, and 32% more likely to die in the 30 days following the procedure.² For male patients there was no difference in outcomes whether they were treated by female surgeons or male surgeons.

Dr Jerath says “We have demonstrated in our paper that we are failing some female patients and that some are unnecessarily falling through the cracks with adverse, and sometimes fatal, consequences.”²

“These results are concerning because there should be no sex difference in patient outcomes regardless of the surgeon’s sex,” she said

“On a macro level the results are troubling. When a female surgeon operates, patient outcomes are generally better, particularly for women, even after adjusting for differences in chronic health status, age and other factors, when undergoing the same procedures.”

The findings have sparked debate in the UK where surgery remains a hugely male-dominated area of medicine and “claims that “implicit sex biases” among male surgeons may help explain why women are at such greater risk when they have an operation.”³

Dr Christopher Wallis, who co-led the study, says that it’s unlikely the findings are the result of technical differences between sexes.

“Both male and female surgeons undergo the same technical medical training. The very large sample size and the examination of many different surgical specialties would have diluted any technical differences between male and female surgeons.”

The researchers say that implicit sex biases, differing communication or interpersonal skills that may influence trust, and variations in decision making and clinical judgement are potential factors that contribute to the disparities in outcomes.²

“Previous research has also shown that symptoms reported by female patients may be under-appreciated in the health care setting (particularly among male physicians). Thus, early symptoms of complications may be missed when they can be mitigated and instead manifest as more severe events,” says Dr Wallis.²

Embedded, Long-Term Sex Biases

Herein lies the problem, or at least a significant part of the problem.

For centuries women’s health and women’s bodies have been misunderstood and largely ignored, found to be far too complicated to include in medical research. And while the gender imbalance among those who practice medicine has slowly but steadily been improved over the last hundred years, it would be fair to say that surgery is still pretty much an

Sex Biases in Medicine

Implicit sex bias is a significant issue in health care, and awareness of it and its impacts on care and outcomes is increasing.⁴ Implicit sex bias is that which the person is unaware of, but which leads to discrimination and reinforces inequity; implicit bias affects clinical judgement and behaviour.

In their *JAMA Surgery* paper, Dr Jerath and colleagues write that gender discordance (e.g. male surgeon-female patient) “is associated with worse rapport, lower certainty of diagnosis, lower likelihood of assessing patient’s conditions as being of high severity, concerns of a hidden agenda, and disagreements regarding advice provided.”¹

Sex bias against female patients is not new. For example, Hoffmann and Tarzian reported in 2001 in the *Journal of Law, Medicine and Ethics*, that “that women are more likely to be given sedatives for their pain and men to be given pain medication. Speculation as to why this difference might exist has included the following: Women complain more than men; women are not accurate reporters of their pain; men are more stoic so that when they do complain of pain, “it’s real”; and women are better able to tolerate pain or have better coping skills than men.”⁵

In a more recent meta-analysis of 77 studies,⁶ researchers found that women with pain are more likely to be perceived as hysterical, emotional, complaining, not wanting to get better, malingerers, and fabricating pain, as if it is all in her head, and that woman with chronic pain are assigned psychological rather than physical causes for their

pain. Additionally, “women, compared to men, received less and less effective pain relief, less pain medication with opioids, and more antidepressants and got more mental health referrals.”⁵

A New Zealand study found that for female patients with male doctors there was an increased likelihood of the practitioner doubting the diagnosis and believing that the female patient had a hidden agenda that she failed to present in the consultation; male practitioners were also more likely to diminish the perceived seriousness of the condition in female patients.⁷ Gross *et al*, conclude that their findings “suggest a need to raise male physicians’ awareness to possible biases when treating female patients. The findings also suggest the need to empower female patients to take an active partnership role to improve their communication with male physicians.”⁷

Even in the Covid pandemic, implicit sex biases against women are evident. Julio Ancochea and colleagues found that women were more heavily impacted by Covid infection than men, in part because most frontline health care professionals are women and also more women are primary caregivers. The researchers found that “both hospitalization and ICU admission were less frequent outcomes in females than males. Unfortunately, basic diagnostic tests such as blood tests or imaging were less used in women.”⁸

They conclude that their results “provide further evidence of the inherent gender bias in the Health System, which is thought to originate in medical school and impacts all aspects of healthcare.”⁸

“old boys club”. In particular, women are under-represented in otolaryngology, plastic surgery, urology, orthopaedic surgery, and neurosurgery.¹⁰ In the US, while women make up 50% of the med school graduates, they make up only 38% of the surgeons; in the UK only 27% of surgeons are female.¹¹

In research for this article, I searched for papers and articles on the gender imbalance among surgeons and found a plethora of data; far too much material to cover here. However, in brief, the gender imbalance is alive and well; whatever strides women have made towards equality, it seems that surgery is a discipline that is stuck in Victorian times.

Women surgeons, both in their path to qualification and in their practice, suffer multiple disparities and inequities:

- women experience disparity and discrimination in training, research, leadership, and pay;¹²
- more women experience negative comments about their gender (36% vs 4% for men), experience gender discrimination (65% vs 10%) and sexual harassment (30% vs 6%);^{12, 13}
- women suffer insufficient support/lack of mentorship, lower levels of respect from both hospital staff and patients (including many assuming female surgeons to be nurses);¹³
- women suffer in a male-dominated culture, which includes exclusion and having to accept the status quo and adapting to fit into the male culture.¹³

Appallingly, the situation is no different in Aotearoa New Zealand, the nation that likes to hold itself up as a bastion of equality and women’s rights. In an investigative piece for the *New Zealand Herald* in 2021, Emma Russell found that top male doctors earn up to \$73,000 per annum more than their female colleagues.¹⁴ Among the Auckland DHBs the discrepancy in pay between male and female specialists was \$14,000 pa in Waitematā to an enormous \$65,000 pa in Auckland DHB, the second worst in the country after Whanganui (\$73,135). In Counties Manukau the discrepancy was \$30,000.¹⁴

It’s not just pay where women suffer. Angela Lim, a medical doctor and chief executive of mental health social enterprise Clearhead, related an instance in which, at a board meeting, a patronising older man commented: “You speak really well, not just a pretty face.”¹⁴

“I have to bite my tongue to not mention that I went to Harvard to complete my research sabbatical and have sat on more boards than he has,” Lim told Emma Russell.¹⁴



The limited research in Aotearoa New Zealand confirms that female surgeons or trainee surgeons suffer the same disparities and inequities detailed in research in other countries.

“Experts say the findings are evidence of alarming gender bias in medicine and highlight how women are being undervalued by our health system, with detrimental impacts on patient care.”¹⁴

Research has found that “Diversity in medicine builds high-performing teams that promote better health outcomes, innovation, performance, and morale.”¹⁰ It seems patently obvious that removing the gender inequities and disparities that female surgeons suffer will go a long way towards improving outcomes for all patients, not just women.

Unfortunately, it runs a lot deeper than just the lack of equality for female surgeons; in fact, you could argue that the experiences of female surgeons, and of female patients at the hands of male surgeons, just mirrors a longstanding attitude to women in medicine and health altogether.

We have written about this in past Newsletters, but it is worth repeating the stark facts of the matter here:

Starting with the fact that “We literally know less about every aspect of female biology compared to male biology.”¹⁵

For example, almost everything we know about heart disease is based on studies of men, despite the fact that heart disease and heart attacks present differently in women. Heart disease is the leading cause of death in women, and although we have fewer heart attacks than men, we are more likely to die. A *Lancet* editorial in 2019 said: “The structural

Surgical Outcomes in Aotearoa New Zealand?

The *JAMA Surgery* paper published in February exclusively investigated Canadian surgeons and patients. A search of the medical literature didn't turn up any other similar research for Aotearoa New Zealand or other countries we typically compare ourselves with.

In research for this article, I searched the Health Quality and Safety Commission (HQSC) website and contacted them. As we publish this Newsletter there is no evidence that this sort of data is collected in a comparable form.

I also sought information from the Health and Disability Commissioner (HDC) on the basis that complaints about surgeons might be a sort of proxy for the Canadian research and that complaints against surgeons provide some insight into whether or not the sex-discordant surgical outcomes found in the Canadian situation may occur here.

There appears to be no data collection and/or analysis at the HDC that would provide any such insight. The closest is data presented at the

2017 HDC Conference in a session entitled "HDC Complaint Data: Patterns and Predictions"⁹ The only remotely useful data in this presentation was the slide comparing complaints against male and female doctors; approximately 75% of complaints against doctors were against male doctors, while male doctors comprise only 60% of the workforce. However, this analysis includes all medical doctors including GPs and psychiatrists as well as surgeons, so has limited usefulness in this context.

The complaints data could be seen as suggestive that male surgeons have more complaints made about them but there is nothing in the data that is collected in Aotearoa New Zealand that we are currently aware of that indicates that actual outcomes differ on the basis of surgeon-patient gender discordance. Despite this, given the implicit sex inequities, biases and discrimination against women in our health system, we would not be surprised to find that surgical outcomes in Aotearoa New Zealand mirrored those elucidated in the Canadian research.

gender bias in cardiology stems from a historical failure to ensure gender balance in cardiology research." Women die because doctors assume that women experience heart attacks the way men do, and "women get consistently worse care... women with heart attack symptoms were less likely to receive aspirin, be resuscitated, or be transported to the hospital in ambulances using lights and sirens than were men."¹⁶

A paper in *Nature* in 2010 concluded that "gender inequalities in biomedical research are undermining patient care." And the authors called "on journals, funding agencies and researchers to give women parity with men, in studies and in the clinic."¹⁷

In 2018, a study on sex bias in clinical trials found that "sex bias is present in current day clinical trials. Despite legislation requiring NIH-funded clinical trials to include women, NIH-funded trials were not better than industry-funded trials at matching the inclusion of both sexes."¹⁸

According to neuroscientist, Dr Rebecca Shankey, for the most part medical research doesn't include female animals and there has been an attitude in the research world that "oh no, females are so complicated, so we just don't study them."¹⁹

She says that "if scientists don't stop looking through a male lens, outdated gender stereotypes will continue to foster dangerous assumptions about the

brain and behaviour, resulting in clinical studies and eventual treatments that don't work equally for all people on the gender spectrum."¹⁹

Dr Daniela Pollak, a neurobiologist, says "We live in a world where the assumption is that males are the standard, the reference population, and females are the ones that are odd."¹⁶

It should be unsurprising to find that women have poorer outcomes from surgery when they are operated on by men. It is part and parcel of a global medical system that:

- does not value women's health enough to learn more about women's bodies, their symptoms and how they experience ill-health;
- does not value women's health enough to learn more about how they experience pain;
- assumes that if it isn't immediately obvious what is causing her symptoms then it must be all in her head, or caused by rampant hormones, or that she is a hypochondriac, has a hidden agenda or is malingering or seeking drugs;
- undervalues women doctors and subjects them not only to discrimination in training, research, leadership, and pay, but sexually harasses them and forces them to work in an environment where other doctors and patients (including some

women) disrespect them and assumes that they are inadequate in comparison with male doctors.

A 2016 Oxford University research paper, while almost six years old, is still entirely relevant. It focuses on the “importance of redefining women’s health as more than [sexual and reproductive health], to extend the definition to include the leading causes of death and disability for women, especially non-communicable diseases]” and the need for a “gendered approach to the collection and analyses of health data, so as to identify and better understand both the biological (sex) and sociocultural (gender) factors associated with differences and disparities in the occurrence and outcomes of health.”²⁰

“...we emphasise the value of a gendered approach to the collection and analyses of health data...”

— Women’s Health: A New Global Agenda²⁰

The authors point out that there has been little recognition that there are differences and disparities in the occurrence, management and outcomes of health conditions in men and women. As a result, data and research findings involving only men were assumed to be relevant for all, that men are the default and what applies to them applies to women. They use the example of ten drugs that were withdrawn from the US market between 1997 and 2000 because of life-threatening health effects; eight of these posed greater health risks for women than for men.²⁰

The Oxford paper states that the current women’s health agenda has an “almost exclusive focus on women of childbearing age [that] effectively discriminates against and excludes those women who do not have children and women who are no longer of reproductive age.”

Among the recommendations of the paper is that:

- governments, health entities and NGOs consistently recognise, promote and allocate resources to address a broader health agenda for women and adolescent girls, with a focus on the established leading causes of death and disability for women and adolescent girls, namely non-communicable diseases;

- the gendered analyses of healthcare statistics is monitored (and policed);
- the pathways and quality of care for women within the healthcare system are examined, including if these pathways differ for men and women;
- evidence-based strategies are identified that could be implemented to ensure women receive the best available care.

Poor surgical outcomes for women with male surgeons is just yet another symptom of a broken medical and health industry that ignores and undervalues women’s health. This situation cannot

continue. In Aotearoa New Zealand, women make up just over 50% of the population, and it is unconscionable that these inequities and disparities in health continue.

The patriarchy needs to “get over itself” and acknowledge the implicit gender biases in our health system that affect both patients and practitioners. When women have their health and well-being needs met the entire country will benefit on a multitude of levels.

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New Birth Injury Bill Perpetuates ACC Biases

By Sue Claridge



ACC Minister, Carmel Sepuloni, responded to pressure last year from Green MPs to amend ACC legislation to cover birth injuries, but the proposed legislative amendment still denies many women the support they so desperately need to recover from birth injuries when they are at their most vulnerable.

In late September 2021, Minister Sepuloni announced:

“Amongst a suite of changes, we’re proposing to amend ACC legislation to cover more injuries experienced by women during childbirth.”

“[Eighty-five] per cent of women in New Zealand experience an injury when giving birth. A small number of these injuries are severe and share similar features to other physical injuries covered by ACC so it’s only fair that they are covered too.”¹

Yet fairness seems to be a concept that only goes so far. When the proposed amendments to legislation were released for public consultation in January, it was clear that not all birth injuries were included in the narrow list of injuries to be covered. In fact, many women would be excluded from cover, such as women injured before the implementation date of 1 October 2022 regardless of the severity of harm; and those with injuries that had they occurred by some other means, would be covered by ACC. For example, broken bones and fractures, including

tailbone, hips, spine, etc. as a birth injury are not covered, which makes little sense when such injuries are covered by ACC if you fall down stairs, get hurt on the rugby field, or get drunk and are injured in a car accident.

In principle the AWHC supports the Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill, and the expansion of ACC cover to include birth injuries. However, we are adamant that this does not go far enough and argued in the strongest possible terms that *ALL* birth injuries should be covered by ACC and retrospectively, so all women can receive the medical care they deserve.

This legislative amendment offered the opportunity to significantly redress the imbalance that disadvantages women in injury cover, yet the authors of the bill have not fulfilled the potential to offer real benefit to women who suffer birth injury through no fault of their own, instead choosing to perpetuate the inequities and discrimination that women have had to bear for five decades.

The existing ACC legislation does not list the injuries covered by the AC Scheme, and includes only broad definitions and some specific examples, such as: as well as external force, trauma as a result of “twisting” of the body can be included.

We see no reason why coverage of birth injuries should be treated any differently and fail to see why some birth injuries are covered and not others. The proposed Amendment Bill lists:

- labial, vaginal, vulval, clitoral, cervical, rectal, and perineal tears
- levator avulsion
- obstetric fistula (including vesicovaginal, colovaginal, and ureterovaginal)
- obstetric haematoma of pelvis
- pudendal neuropathy
- ruptured uterus during labour
- uterine prolapse

However, the proposed Bill omits or is unclear on

- broken bones and fractures including tailbone, hips, spine, etc;
- various other types of prolapse: bladder, bowel, rectum, urethra, or small intestine resulting from muscle strain;
- muscle or ligament damage other than levator avulsion, which can be causative of prolapse, such as damage to the sacrospinous ligament;
- nerve damage other than that to the pudendal nerve;
- fissures,

It is entirely inconsistent to specify in the legislation which birth injuries are to be covered by ACC when, for example, there are no such lists of injuries to be covered that might be suffered during the playing of various sports (e.g. rugby, skiing, etc) or in the course of employment (e.g. farming, forestry, construction), or in road accidents.

It is also entirely inconsistent that the same injuries suffered during other activities are not covered in the context of labour and birth. For example, bones broken during the playing of sports, or falling off a ladder or down stairs are covered, but bones broken during labour and birth are ignored. Similarly, ligament or muscle damage from sporting pursuits or even just tripping while walking on the footpath, are covered, but in the context of labour and birth levator avulsion is the only muscle injury covered and other muscle or ligament injuries are not.

We recommended in our submission that there is no specified or restricted list of injuries included in the Amendment Bill and that claims for ALL birth injuries are able to be covered and assessed by ACC.

Women Injured Before October 2022

Another failing of the Bill is that it only includes parents who give birth after the 1st of October 2022. While we understand that ACC can't allow a "free for all" there needs to be recognition that women who have suffered traumatic birth injuries in the past still suffer and are unable to get the treatment they desperately need to live something that even remotely resembles a normal life (see Emme's story on page 19).

Equitable access to medical care for all must be a priority for ACC. Parents who have existing injuries should have cover too!

This legislation should apply retrospectively to allow parents dealing with the long term impacts of birth injuries to get help for ongoing treatment needs.

It is unconscionable that those who have suffered traumatic birth injuries and continue to suffer, will be prevented from accessing rehabilitation and treatment that others will get from the 1st of October.

Ministers Sepuloni and Verrall have acknowledged the inequities and disparities in the existing ACC legislation, and have claimed that the proposed changes to the legislation "aims to improve gender balance, fairness and equity in the ACC scheme, making support more accessible to those who need it."

They also stated that they know that "women make fewer claims than men, have fewer injuries covered by the Scheme than men, and each woman's claim costs the Scheme a third less than a man's on average in entitlements."

There can be no justification for denying women injured before the 1st of October cover under the legislative amendment. There must be a sunset clause in the legislation to ensure equity and fairness for those who still suffer the debilitating impacts of birth injury.

Inherent Discrimination Against Women in ACC

In 2021, in a briefing to ACC Minister Carmel Sepuloni², ACC admitted that there are significant biases and discrimination against women in ACC coverage.

“Differences in men’s and women’s receipt of cover and entitlements ... are longstanding, and are likely to arise from a broad range of societal, institutional, community and individual factors. Some of these may reflect inequities (unfair and avoidable differences), while others may arise from inherent differences between sexes (such as anatomical differences).”²

ACC found that fewer women than men lodge claims with ACC, and more women’s claims are declined. Between 2015/16 and 2019/20 decline rates for women rose from 2.2% of lodged claims to 2.6%, while for men the decline rates went from 1.9% to 2.1%.² More men tend to work in higher risk sectors where injuries are more likely (e.g. forestry and farming) and participate in riskier or more injury prone non-work activities. However, some of the differences in the levels of compensated injuries are a result of what ACC defines as an injury, and these definitions favour the types of injuries typically suffered by men and consequently disadvantage women.

In an interview with RNZ in September 2021,³ Carmel Sepuloni said that the changes covered by the Amendment Bill will help 17,000 to 18,000 women each year, and cost ACC around \$25 million annually.

Over the five years to 2019/20, between 915,000 and 988,000 claims were lodged for women each year, compared to between 989,000 and 1,085,000 for men. With an additional 18,000 claims for birth injury per year this would see women’s claims rise to between 933,000 and 1,006,000, still almost 80,000 short of men’s claims.

While extending the range of injuries and treatments covered to include ALL birth injuries to both mother and the baby, and including PTSD and PND/PNP for the mother would increase that estimate of new claims, given the comparison above, there is plenty of room for an equitable compensation system for birthing women and their babies.

Mental Injury from Birth

AWHC believes that mental injury suffered as a result of the labour and birth should also be covered as a birth injury. Many women suffer with mental health, including postnatal psychosis (PNP), postnatal depression (PNP) and post-traumatic stress disorder

(PTSD) after a traumatic birth and should receive support to recover, regardless of whether there is also a physical injury.

Research by Dr Stella James in 2015, found that women who have gone through traumatic child-birth experience the same PTSD symptoms as those of PTSD from other traumatic events.⁴ More recent research (2021) found that trauma during labour and birth (such as emergency childbirth/Caesarean and distressing events during childbirth) significantly increased the risk of the development of PTSD in mothers following childbirth.⁵

ACC already covers mental injury, such as PTSD, both when there is and when there is not a physical injury, such as when a person has experienced, seen or heard a traumatic event. Mental injury, including PNP and PTSD, arising from a traumatic birth should be treated no differently.

Injuries to the Newborn

AWHC strongly believes that ACC cover must be extended to include injuries to the baby. Birth injury cover should be available to babies who experience injuries during the birthing process.

Being a new parent can be difficult enough, and this is made so much harder when a newborn has injuries or disabilities because of the birth process. Parents need support during this time and deserve equitable ACC cover. AWHC recommends that the Amendment Bill includes provision for coverage of birth injuries to infants, ending the current inequities that allows ACC to cover only babies who suffer a ‘treatment injury’ during birth.

Obligations to Te Tiriti o Waitangi

AWHC believes that all new legislation must address Te Tiriti, uphold the Crown’s obligations under Te Tiriti and honour the principles of Te Tiriti. This is particularly critical where the legislation deals with issues and situations that have been shown to perpetuate inequities and disparities for tangata whenua.

In 2021, ACC found that there is consistent evidence that Māori benefit less than non-Māori from ACC. Māori wāhine are doubly disadvantaged; accepted claims among Māori wāhine are well below those of men of the same ethnicity, and compensation payments are lower still.

Briefings² to ACC Minister, Carmel Sepuloni, found that lower lodgement claims for Māori were not believed to be indicative of fewer injuries, “but rather, of barriers to accessing the ACC scheme.”

Māori are less likely to be referred for certain treatment than non-Māori despite having injuries that are covered by ACC, and they are more likely to have poorer long-term injury outcomes, including a higher rate of death from injury.

It was encouraging to see ACC acknowledge not only conscious and unconscious racism in our health system and among practitioners, but the ongoing impact of colonisation on Māori, saying that “many of the safety risks faced by Māori can be traced directly to alienation from whenua and traditional ways of life as a result of colonisation.”

It is time that legislation acknowledged the inequities and disparities suffered by Māori, particularly in health, and the Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill needs significant improvement to support tangata whenua who give birth and their pēpi.

A Te Ao Māori view of maternal health is holistic and recognises the importance of whānau well-being, and the connection between oranga whānau, oranga tinana, oranga hinengaro, and oranga wairua. This legislation should cover all injuries related to birth so that whānau can get holistic maternal healthcare and do not have to face bureaucratic barriers. The Accident Compensation Act also does not mention Te Tiriti O Waitangi once. A commitment to Te Tiriti and equitable care for Māori should also be embedded in the legislation so that ACC can work toward bridging disparities for Māori.

Prevention of Birth Injury

APHERM (Advocating for Pelvic Health Empowerment and Rehabilitation for Mothers) is a multidisciplinary group of healthcare professionals and consumers who came together out of concerns about increasing pelvic floor disorders and injury occurring pre and post birth

They have a special interest in the proposed changes to ACC legislation to cover birth injuries, and like AWHC, they have major concerns about the inadequacies of the proposed Bill and the limitations of cover for women injured during labour and birth.

Before the Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill was released for public consultation, APHERM had launched a petition seeking improvements to rehabilitation care for New Zealand women post-birth.⁶

APHERM says that “women are struggling unnecessarily to get the help they need, and because they felt that women’s health was not, and is still not a priority for either the government or ACC.”⁷

They point out that ACC’s vision statement is to “create a unique partnership with every New Zealander, improving their quality of life by minimising the incidence and impact of injury.”

“Taking into consideration this gender bias, reducing the incidence and severity of injury seems wishful thinking without a clearly defined women’s health prevention of injury policy,” says APHERM. They go on to say that “there seems to be very little focus at ACC on prevention of injury for women and this must change.”

They believe that prevention of injury “should be at the forefront of ACC’s changes to policy and visible within the implementation of this bill.”

AWHC agrees that prevention is a vital issue. As with every other area of health, prevention must be a focus, as it not only reduces ongoing individual, whānau and community impacts and the burden of disease and disability, but it will significantly reduce the cost to the Aotearoa New Zealand and the tax-payer through ACC and provision of treatment in the health system.

APHERM’s petition and submission on the proposed amendment to the ACC legislation focuses on the prevention of pelvic floor disorders. Their aim is all women in Aotearoa New Zealand have access to publicly funded pelvic floor health pre and post birth by 2025.

Alongside the provision of funding, they are advocating for better education, screening, and treatment during pregnancy and after delivery by all multidisciplinary maternity care providers (pelvic health physiotherapists, continence nurses, midwives, practice nurses and GPs).

“New Zealand women lack rehabilitative education, pelvic health maternity checks and funding for birthing rehabilitation. Our system does not nurture and support the mother and her body is not supported when it comes to recovering from childbirth.”

— APHERM⁶

Contrasting Stories from Women Injured During Labour

Ruby's Story

Ruby suffered a serious pinched nerve during the premature birth of her twins. She was lucky that her treatment was covered by ACC and, perversely, "lucky" that her babies had to stay in NICU for an extended period. This meant that she had the time to begin her recovery without the extraordinary workload that goes with caring for newborn twins: breast-feeding, carrying, lifting, bathing her babies while suffering significant and debilitating pain.

Ten months on from her birth injury she has just finished treatment. She can't imagine what sort of dark place she would be in now if she had not had her treatment covered, and had not had that critical time early in her recovery not having to physically care for her babies, despite being desperate to have her babies home with her. But the pain and debility she experienced impacted on her mental health for a period and she shudders to think how badly it may have turned out for her had she not had that important ACC cover.

She feels for the women with worse birth injuries that they are not covered by ACC, and wonder how they cope, how they get through what is already a demanding and difficult time for many.

Emme's story

Emme's story couldn't be more different from Ruby's. Four years after the birth of her first child Emme suffers every day with the pain and debilitation caused by a birth injury.

Next month will mark her beautiful boy's 4th birthday, and also four years off suffering since her traumatic injury brining him into the world.

During the birth, Emme suffered a bilateral pelvic avulsion, which means that the two tendons that attach pelvic floor muscles to the pelvic bones, snapped. Unfortunately, the extent of her injuries went undiagnosed for a long period of time.

As happens when an Achilles' tendon snaps, it is incredibly painful, and reattachment is time critical, with several weeks' recovery including physio, but undiagnosed her injury went untreated. In addition, she suffered a third degree perineal tear from her urethra to her anal sphincter. Emme now suffers from a prolapsed bladder, cervix and rectum. There's nothing to hold her pelvic floor from above (tendons) and there's nothing to hold it all in from

below due to scar tissue and what feels to her like an imploding vagina.

"It's a sort of prolapse trifecta, but not one where I win anything; I'm not even given any support or assistance," Emme says.

In the initial repair of her perineal tear the stitching was done too tightly:

"My perineal area felt over-stretched and like it could burst spontaneously for the next two years, until I tore again birthing my next baby."

The birth events that caused these traumatic and debilitating injuries was also psychologically traumatic.

"Post-partum, I would sit down in a chair or couch only to leap up from the sharp pain on contact. I suffered anxiety any time I needed to go to the toilet and I started to suffer from urinary incontinence and frequency, as unbeknown to me I was unable to empty my bladder."

Emme worked with a pelvic floor physio at her own expense while on one income (due to maternity leave). There was no improvement, and after over a year she was desperate to know why nothing was getting better; if anything, things were getting worse. At this point she had lost her job, in part because she had to take so much time off, and take so many toilet breaks both in the office and out on the road in her sales rep job. She was struggling to run around after her son and wet herself every time she picked him up for a hug, put him in his car seat, or into a swing.

"I was NOT the mum playing on the playground with him that I always wanted to be."

Emme's physio confessed that she was stumped as to why there was no improvement, as Emme was doing all her pelvic floor work perfectly and sticking to her training.

"I saw a hospital gynaecologist who assessed me, and told me my prolapse was 'NORMAL'. When I broke down saying I just wanted to go for a run or chase my son in the garden, she laughed at me and said "You can still do those things, wear a pad... it's not like your vagina is going to 'fall out'."

"I felt invalidated and as though I'd been making it up. I tried running. My vagina DID 'fall out'."

Pregnant again and jobless, worried about money, a desperate Emme decided to see a private

gynaecologist, who promptly diagnosed the avulsion, and three prolapses.

“She said I would need to have a hysterectomy, surgical mesh sling, and a further surgery to reshape my vagina. Running did cause harm and I will never run again; certainly, I’ll never be able to jump on a trampoline with my kids. [The gynaecologist] was horrified at the DHB treatment and reiterated I would not be covered for anything by ACC. I often think about all that money on physio, and it was never going to work if the pelvic floor is paralysed from avulsion.”

“Now, I need to decide that I am absolutely done having children before I can have the surgery. I have to find a job I can physically undertake given my urinary frequency and that I can’t lift much, in order to pay for surgery that won’t last. I will need repeat procedures over my lifetime. I’ve had to pay for pessary devices that don’t work, they just fall out. I’ve had to ditch tampons and period cups for period knickers and pads because I am so misshaped my body can’t ‘hold on’ to any cup, tampon or pessary. I have constant abdominal aches and pains. You can imagine this takes a toll on my relationship too.”

Emme is overwhelmed and daunted by what has happened; she has a huge sense of shame in talking about what has happened and the debilitating impacts of her birth injury.

“It isn’t my fault – but who wants to go to make some noise to change a system when it involves

putting your hand up and saying, ‘hey I pee myself frequently and I have a vaginal prolapse’.”

“Women like me are far too young to be told they have the pelvic health expected of an 80 year old woman, and that there’s no funding or support available, because it was less of an accident than the fist of a man who intentionally punched an object (perhaps a human) in rage – which WOULD be covered by ACC.”

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PREVENTION
IS BETTER
THAN CURE



Finally, A Focus on

Cancer Prevention

By Sue Claridge

“Our aim is to identify ways that we can create environments that support people to stay well.”

— Professor Diana Sarfati

Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report¹

As someone who has advocated for years for a greater focus on cancer prevention, who worked for 13 years as a researcher and writer for a breast cancer organisation with a specific focus on promoting cancer prevention, this statement the foreword to the *Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report¹* soothes the soul and buoys the spirits.

Prevention of illness, and promotion of staying well throughout life, has been a poor cousin to treating illness via a reductionist pharmico-medical model of health for far too long. Other major causes of ill-health, such as cardiovascular disease and diabetes get more traction in terms of prevention education through a variety of media. In the meantime, cancer has languished on the prevention front, with many people still believing that it is a random disease, an alien invader, an assailant from outside. Aside from preventing lung cancer through not smoking and melanoma through UV radiation avoidance, many still believe there is nothing that can be done to reduce the risk of cancer.

Despite this enduring belief, the International Agency for Research on Cancer (IARC) and the World Health Organisation (WHO) have for many years stated that one third or more of cancers worldwide could be prevented if we addressed five modifiable lifestyle choices – body weight/BMI, diet, exercise, tobacco smoking and alcohol consumption.^{2, 3}

Based on current knowledge, as many as another 20% of cancers are attributable to other modifiable risk factors, including environmental pollution, occupational carcinogens, UV and ionising radiation (including medical radiation) and infections.^{2, 3}

In 2020, Aotearoa New Zealand had the second highest incidence of cancer[†] in the world (second only to Australia), and the second highest rate of cancer in women (again, second only to Australia).⁴ Cancer is the leading cause of premature death in 30 to 69 year old New Zealanders;³ it the leading cause of health

[†] all diagnoses for all cancer types/sites.



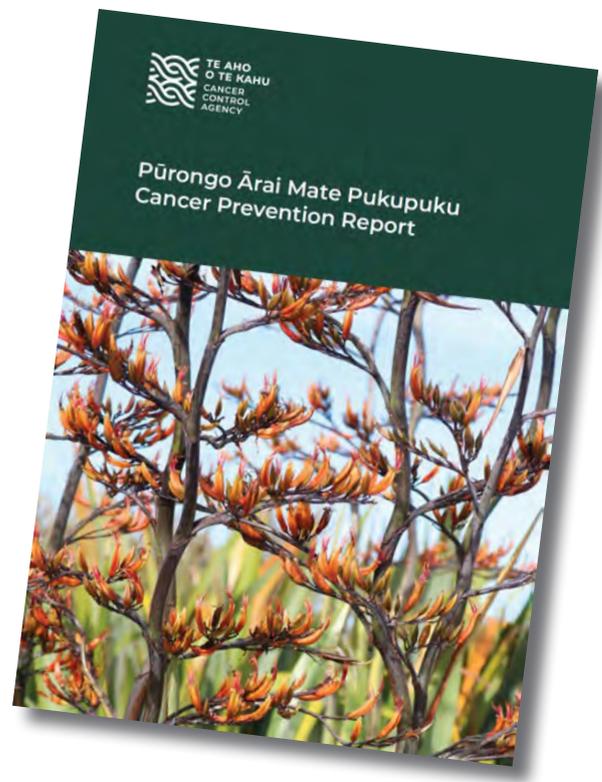
Professor Diana Sarfati

loss in Aotearoa New Zealand and approximately 25,000 people are diagnosed in this country each year.¹

Prof. Diana Sarfati, Chief Executive and National Director of Cancer Control, states that “half of all cancers are potentially preventable, by reducing everyone’s exposure to the cancer risk factors present in our environments.”¹ The *Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report* published in February this year “focuses on what actions Aotearoa can take to stop cancers developing whenever that is possible.” Prof Sarfati states clearly what those advocating for a greater emphasis on prevention have believed for years – that stopping cancer before it starts is the “very best possible cancer outcome”.

Even in those cases where the confluence of early detection and improved treatment leads to what the most optimistic might describe as a cancer “cure” in some types of cancer, prevention is still immeasurably better. Prof Sarfati states clearly that those with cancer will receive the best possible care; treatment is not ever going to be abandoned just because the focus should be on prevention.

Despite what many in the cancer industry fear, that in addressing prevention, it effectively becomes a “blame game”, prevention is about education and about policy. It is about ensuring that everyone knows what they can do to reduce their risk and ensuring that citizens of Aotearoa New Zealand have a Government and health agencies focused on reducing environmental exposures beyond the control of individuals.



Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report

The *Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report* starts with the case for cancer prevention, followed by sections on each of six significant factors that contribute to the development, or increased risk, of cancer:¹

- tobacco,
- alcohol,
- nutrition and excess body weight,
- insufficient physical activity,
- exposure to ultraviolet radiation,
- chronic infections.

It is notable that these are all modifiable factors and that they have a component of personal influence; however, there many contributors that are hard for people to address individually – environmental pollution, occupational carcinogens and other forms of radiation (including medical radiation). There are also gendered aspects to cancer prevention and cancer risk factors (see side-bar page 23).

The report points out that if 30 to 50% of cancers globally are preventable, in Aotearoa New Zealand that would mean 7,800 to 13,000* fewer people would develop cancer each year.¹

The benefit to New Zealanders of preventing cancer cannot be overstated:

* based on the 26,000 people diagnosed with cancer in 2018¹

Gendered Aspects of Cancer Prevention

In the world of medicine and health, where women are so often discriminated against and are at the sharp end of inequity and disparity, women/wāhine in Aotearoa New Zealand do a bit better than men in the cancer stakes. The International Agency for Research on Cancer (IARC) estimate that 42% of New Zealand men and 34% of women will develop cancer before the age of 75%; the risk of dying of cancer before 75 years is 10.7% and 9.3% respectively.⁵

The *Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report* does not take a gendered approach to the discussion of cancer prevention, either generally or in discussion of specific cancer risk factors. This is not particularly surprising, as a gendered analysis of women's health needs in Aotearoa New Zealand is almost entirely lacking (as it is in most other parts of the world) and something that we, among other organisations, lobbied for in our recent Pae Ora (Healthy Futures) Bill submissions.⁶

Given that in 2019, 12,384 women/wāhine in Aotearoa New Zealand were diagnosed with cancer,⁷ it is disappointing that the gendered aspects of cancer risk do not appear to have been considered.

Women often live stressful, complex, time-poor lives, often juggling multiple roles – parent/carer, worker, volunteer, etc. Do they have time and money and access that would enable them to make better choices about food and exercise? Does their limited income after necessities like housing, clothing their children, childcare, etc. allow them to spend money on often expensive fruit and vegetables. Or do they use smoking and alcohol to take time out for themselves or to cope with the stress and increasing complexity of their lives?

The difficulty is that, internationally, research into many risk factors has focused primarily on white men.⁸ Kim and colleagues report that “sex differences influence cancer susceptibility at the genetic/

molecular levels. Sex hormones also negatively or positively affect the development of various cancers.” However, despite that they point out that for years animal studies and clinical trials used males alone and excluded females.⁹

Kim *et al.* report that there are sex-specific differences in the incidence and mortality associated with various cancers. For example, women have a higher incidence of thyroid cancer, and while more men develop colorectal cancer women are more likely to develop right-sided malignancy, which is associated with a higher severity of cancer compared with left-sided disease.⁹

Researchers from the Sookmyung Women's University in South Korea, delve further into the gendered facets of colorectal cancer:

“Diet is one of the most closely associated environmental factors in colorectal cancer development. Dietary factors to increase or decrease the risk of developing colorectal cancer are continuously updated based on large scale cohort studies. However, only a half of studies reported sex-specific risk estimates despite potential sex-associated differences between dietary factors and colorectal cancer risk. Given that there are sex- and gender-specific differences in the biological responses to dietary components, it is necessary to analyze and report gender-specific risk estimates to provide better guidelines for cancer prevention strategies.”¹⁰

Notably, colorectal cancer is the second most diagnosed cancer in women/wāhine in Aotearoa New Zealand.⁷

The limited research available has made it clear that, until there is a gendered analysis of cancer risk, prevention strategies in Aotearoa New Zealand cannot be optimised for half the population.

“In 2019, the people of Aotearoa lost the equivalent of over 220,000 years of life in full health due to cancer, making it the leading cause of health loss. Yet if all modifiable cancer risk factors had been addressed, about 40 percent of that health loss could have been prevented. This would mean that together the people of Aotearoa would have over 90,000 more years of life in full health and out of the approximately 10,600 New Zealanders estimated to die each year from cancer, almost 4,400 fewer people would die.”¹

Giving examples the report states:

“[By] addressing modifiable risk factors, we could prevent:

- around 75 percent of the health loss from lung cancer, mainly by reducing smoking
- 50 percent of the health loss from uterine cancer by reducing high body mass index (BMI)
- 65 percent of the health loss from bowel cancer by reducing dietary risks, alcohol use, high BMI, smoking and physical inactivity.”¹

It was great to see the report addressing the socio-political determinants of health, saying that “social,

political and economic factors (which sit outside of the health system) are especially influential – including the role of colonisation and racism in creating and perpetuating inequities,” and acknowledging the role that these factors have in behaviours that contribute to cancer development, such as tobacco and alcohol use and poor nutrition.

The report also acknowledges that the wider environments in which people live and work also exert influence outside their control. It cites the issue of more fast food and alcohol outlets in socioeconomically deprived areas where more Māori and Pāsifika families live, and the fact that supermarkets in low-income areas stock a higher ratio of unhealthy to healthy foods compared with high-income areas, as examples of how control is taken away from the individual. These environmental factors have “have real downstream consequences; for example, Māori and Pacific peoples have a higher proportion of obesity-related cancers.”¹ The report identifies that making healthy choices that would reduce the risk of cancer are infinitely harder, and unfairly so, for certain groups of people and communities.

Of course, the six modifiable factors mentioned above, are also major contributors to other non-communicable diseases, such as cardiovascular disease and diabetes and this does not go unremarked on in the report. Addressing cancer prevention will also go a long way towards reducing the burden of these other non-communicable diseases and the associated loss of life and healthy years. Reducing the burden of cancer and cardiovascular disease and diabetes on our health system will free up funding and other resources for use in other areas of health – the flow-on effects are significant, not just for individuals and their whānau, but for the nation as a whole.

The Report's Conclusions

The *Pūrongo Ārai Mate Pukupuku | Cancer Prevention Report* finds that there are many common themes across the cancer risk factors, and concludes that in Aotearoa New Zealand cancer can be prevented by:

- reducing the availability and accessibility of harmful products that increase the risk of cancer (e.g. tobacco and alcohol);
- increasing the availability and accessibility of commodities that can reduce the risk of cancer (e.g. healthy food);
- improving physical environments or settings;
- restricting the advertising or marketing of some products, such as alcohol and unhealthy food and drinks;

- regulating the contents of certain products (e.g. the amount of nicotine in cigarettes, or the amount of salt, sugar and fat in packaged foods)
- improving health services for those particularly at risk, such as by ensuring access to safe injecting for people who inject drugs, and effectively identifying and treating individuals with chronic infections.¹

The *Report* finds that most of the actions that need to be taken are within the sphere of influence of central government and local government, and focuses on “changing environments rather than relying solely on changing individual behaviour... what Aotearoa can do to make healthy choices easy choices.”

In taking action to prevent cancer “the gains are big, the potential to reduce inequities is significant, and the end-results are sustainable.”¹

There really is no such thing as “cancer control” unless cancer prevention is a significant part of the equation. It is hugely exciting for Aotearoa New Zealand that there now seems to be a genuine intention to address cancer prevention and risk reduction in a meaningful way.

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