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ANMF (Vic Branch)

Submission:

Inquiry into Women's Pain

Safer Care Victoria.

Via Email:

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The ANMF (Victorian Branch) (ANMF) represents more than 100,000 nurses, midwives, and personal care workers (the latter predominantly in the private residential aged care sector). Our members are employed in a wide range of enterprises in urban, regional, rural and community care locations, within the public and private health and aged care sectors.

Our core business is the representation of the professional, occupational health and safety, continuous professional development programs and the industrial interests of our members and the broad professions of nursing and midwifery. We participate in the development of policy relating to nursing and midwifery practice, professionalism, regulation, education, training, workforce, and socio-economic welfare, health and aged care, community services, occupational health and safety, industrial relations, social justice, human rights, immigration, foreign affairs, and law reform.

There are over 90,000 ANMF members who are women, this is 89% of our membership. Most members, wherever they work, assist women, and have experienced, professionally and personally, the impact of the attitudes towards women's pain. As such, ANMF included our membership in the development of this submission through an ANMF survey, to which 785 female members responded in just four days. ANMF officers also conducted interviews and focus groups with nurse/midwife leaders working in women's health and wellbeing across women's health, mental health, and research.

The inquiry Terms of Reference clearly outline the differences in women and men's experiences and response to pain, including the low rates of treatment for chronic pain in women. While it is important to acknowledge that women experience pain differently to men, and often with more severity and over a longer period, it is critical that this inquiry results in action that improves attitudes towards women's health and women's pain, and in turn improves women's access to treatment for conditions associated with pain, or that cause pain.

ANMF recognises that the scope of the inquiry into women's pain includes providing women and girls the opportunity to express their experiences with pain and pain management, including the enablers and barriers when accessing healthcare treatment and services for pain conditions, and to identify opportunities to improve access to, and treatment of pain conditions including improved models of care, workforce skill mix and equity outcomes.

ANMF has gathered advice from our members in relation to their personal and professional experiences of pain (including that of their patients), the barriers to clear and effective treatment for pain and conditions causing pain, and recommendations to improve the current issues related to women's experience of pain. The results to the survey and focus groups was significant and insightful, highlighting both the prejudice and barriers that block women from accessing treatment and care, as well as providing effective solutions to improve access and care. This short submission does not do justice to the information that was gathered through the survey and focus groups, or the enthusiasm with which our members responded to the survey. There is an important story about women's health and pain experiences to be told through engagement with industries with strong representations from female employees. The experiences of nurses and midwives are particularly relevant to the discussion because they provide important personal and professional insights. ANMF thanks those members who responded and is available to provide follow up information and data from the survey and organise forums for members to further communicate their experiences to the Victorian Health Minister and other representatives, to assist in informing this process.

Treatment of women's pain – normalisation and dismissal

As the Terms of Reference for this inquiry have stated, it is understood that women experience more pain than men, and that pain is often dismissed or minimised by health professionals.¹ Further, a report released in 2022 by the Australian Bureau of Statistics (ABS) demonstrates a difference in the impact of these attitudes to women's pain on their ability to work as compared to men. The report states that 73.9% of women aged 18 years and over experienced physical pain, compared to 68.2% of men; and 66.1% of women aged 18 years said their pain interfered with work, compared to 58.4% of men.²

It is well established that gender bias in medicine is a barrier to women accessing effective healthcare and pain management, negatively impacting women and girls. The length of time

¹ Williams, A. 2021 Women's pain is routinely underestimated, and gender stereotypes are to blame – new research, The Conversation <https://theconversation.com/womens-pain-is-routinely-underestimated-and-gender-stereotypes-are-to-blame-new-research-158599> Accessed February 2024

² Australian Bureau of Statistics 2022 Stressors and bodily pain: Key findings on experience of stressors and bodily pain in Australia <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/stressors-and-bodily-pain/latest-release> accessed February 2024

that it takes to receive a diagnosis of endometriosis is an example that is often given to illustrate this discrepancy in health equity and the lack of focus and research in relation to women's health. However, recent information related to the inequity of access to cardiovascular treatments is another example that clearly highlights this bias and the significant impacts that this has on women's health and well-being. Information available through the Heart Foundation states that women are less likely to receive treatment for heart attacks or angina in hospital, they are delayed in receiving lifesaving treatments, and that women have poorer outcomes compared to men.³ This inequity of access to treatment impacts outcomes for women and demonstrates the seriousness of this situation for the health and wellbeing of over 50% of the population.

This disparity is even more distinct in the treatment of pain in the maternity space. Women are expected to manage pain across the continuum of pregnancy and are not afforded the appropriate pain management. As an example, women who have had an episiotomy/perineal tear, caesarean section are afforded less pain relief, expected to care for their newborn with minimal assistance, are experiencing an ever-reducing length of stay in public hospitals with reduced at home domiciliary care, with little recuperation and recovery time all while caring for a family. Men on the other hand who have had vasectomy or abdominal surgery are typically provided with a cache of pain relief, appropriate length of stay and advised to rest for a nominal time at home before recommencing their usual routine.

The impact of mismanaged pain was clear in the responses we received from ANMF members. The survey was up for just four days and nearly 800 nurses and midwives responded to the survey and the stories they tell continue this narrative. Their firsthand experiences of pain reveal that, despite being experienced at dealing with the health system and with medical staff, even health literate nurses and midwives are feeling dismissed, or having difficulty accessing comprehensive healthcare for their pain conditions.

They are also very aware that the inequity and bias extends to their female patients. Of the members who responded to the survey:

³ Heart Foundation Australia 2021 [Women and heart disease, Information and resources for healthcare professionals](#). Accessed March 2024

1. 73% indicated that in their professional experience women's pain is treated differently to men's pain.
2. 78% indicated that women face barriers accessing clear and comprehensive healthcare planning to assist in diagnosing their chronic pain.
3. 76% indicated that women face barriers accessing clear and comprehensive healthcare planning to assist managing their chronic pain.

In relation to the bias associated with women and their pain, they made the following comments:

Work on a mixed specialty surgical ward. PRN paracetamol for gynaecology patients who describe 10/10 pain as first line and to "wait and see if that helps", whereas all other surgical patients get 2-3 lines of analgesia charted immediately at any instance of pain.

Multiple colleagues judging young female patients subjective pain scores, calling them "precious", "princess" or "overreacting".

Women are often viewed as being less tolerant to pain than men so when they present we think that the pain they are experiencing is less than men.

There is a stigma that 'women are meant to feel pain'. Many women with chronic pain are so used to their pain that they don't speak up unless they are truly dying in pain and then the pain is treated as base level with basic analgesics which the woman would not usually take because she knows they do not assist her pain anymore.

Men are believed a lot sooner and treated a lot sooner. They're often given more options. I've watched a man with a carpal tunnel be written up for 20 mg of iv [intravenous] morphine but a woman with a full reproductive system removal gets written up for only a Max of 10 mg of iv morphine. We are treated different and are often labelled as emotive or anxious.

Women are often treated in a dismissive manner by male medical professionals.

Often they demonstrate little empathy and most of the male medical professionals have little or no knowledge and understanding of menstrual pain and the hormonal challenges that the pre and post menstruation causes.

The nurse/midwife leaders who attended the focus groups identified four main explanations for the inequity:

1. The normalisation of women's pain that then results in women ignoring their pain, or 'soldering on.' For example, young women might accept severe and debilitating pelvic pain associated with their menstrual cycle, or pain during pregnancy, birth and breast feeding, because their mothers and grandmothers had the same issues, or because they are told they are overreacting. In the case of severe period pain, young women may miss school or work because of the severity of their symptoms, and yet they are expected to accept these circumstances and so they stay silent.
2. Gender bias: many practitioners dismiss a woman's pain as either overrated or psychological. The stereotype still exists that men are less likely to complain and/or have a higher tolerance to pain, yet the evidence is perhaps to the contrary. Focus group participants who work in women's health spoke about the dismissal of pain associated with every stage of a woman's life and the lack of knowledge amongst practitioners for conditions like premenstrual dysphoric disorder (PMDD) or endometriosis. This lack of awareness results in women having to see multiple practitioners before they can access effective healthcare, even just to get their pain investigated, let alone diagnosed and the cause treated. Focus group participants said a lack of wrap-around, multidisciplinary care that would both prevent pain conditions and ensure that women have access to effective treatment beyond the medical model means care is costly, disjointed, and inefficient. For example, menopause causes conditions that result in women experiencing significant pain conditions and an increased risk of serious health conditions, however treatment is rarely considered beyond medication for pain, hormone replacement or anxiety. Increasing access to nurse/midwife led sexual health clinics, specialist physiotherapy and exercise programs and dieticians for menopausal women would be one initiative that could

assist in developing a whole of health approach to what is a transition that every woman can expect to experience.

3. Lack of funding and research into women's health and their health response to treatments was also raised. Funding and research have commonly been based on men's health responses and men's healthcare needs because of ongoing gender bias and male healthcare leadership in Australia. This lack of funding and research into women's health means there are limited treatment options for women, delayed diagnosis or misdiagnosis, and limited understanding of conditions common to women (endometriosis, autoimmune conditions, and osteoporosis).
4. The stigma associated with women's reproductive health and the social bias and stereotyping women are subjected to in relation to pain, results in their staying silent when they know that there is something wrong with their health, for fear that they will not be believed or they will be labelled as hysterical, or 'just' anxious or depressed.

In short, the bias and dismissal that many women have already experienced results in efforts to ignore the pain until it becomes unbearable because women expect their pain will either be minimised, or the pain will be misdiagnosed as normal pain (particularly if it is pelvic pain) that can be treated with over-the-counter pain medication, or as discussed earlier put down to anxiety, or another psychological condition; or the woman will be treated as if she has over exaggerated the level of pain.

When a woman is from a marginalised community or group, or is isolated by health or social circumstances, for instance those women in culturally and linguistically diverse (CALD) groups or who suffer from a mental health condition, their ability to access comprehensive health care planning for their pain condition is further encumbered as a result of the additional bias they face, that is because of racism or social stigma.

A focus group participant who works in the women's prison system said accessing healthcare services for women as they exit the prison system was nearly impossible, with bail and other follow up arrangements, housing, Centrelink, cost of healthcare and domestic violence just a few of the many barriers that these women face. Already dealing with precarious conditions, they are forced to navigate medical services that rarely bulk bill and, as a result, they may have

to choose between organising food for their children or getting an appointment with a GP, if in fact they can get enough time with a GP who will properly assess their health concerns.

This is also significantly worsened when women live in rural and regional areas that may not have access to women's health support and traditionally have lower incomes. These women have severely limited access to GPs, let alone bulkbill GPs and specialist women's health clinics. Many rely on under resourced nurse/midwife led services or Maternal Child Health Nurses for advice regarding their healthcare and pain management. These practitioners have told us that they struggle getting suitable services for the women who are in most need and they desperately need well-funded, specialist wrap around services, that include initiatives like access to specialist women's health physiotherapists, medical imaging and other diagnostic services, lactation consultants, endorsed midwives and nurse practitioners to help women access basic healthcare and pain management.

Further, it must be acknowledged that there is racism in our health system. Repeatedly we were told by participants that women from CALD communities are often called hysterical or have their pain minimised. Their language and cultural barriers already make accessing healthcare harder, but they are also then subjected to racial stereotyping and their pain is dismissed and not properly treated. This was raised in the focus groups and surveys with several participants indicating that medical, nursing and midwifery staff make racist comments about women from culturally diverse backgrounds and do not attend to their pain as readily.

Implications of the mismanagement of women's pain conditions

Barriers to effective diagnosis and treatment for women with a condition that causes acute or chronic pain have significant implications for the woman, her family, the community, and the Australian economy. We asked nurses and midwives how the misdiagnosis or mismanagement of their pain had impacted their personal and professional lives, and the results were, although expected, concerning and costly:

1. 89% of respondents said they had experienced acute pain and over 66% of those felt dismissed by health professionals in relation to their acute pain, and 53% said the response was negative.

2. 74% of respondents suffer with a chronic pain condition and 59% said they had either a negative or mixed response (positive and negative) from health professionals. Only 20% had a positive response from health professionals overall. Twenty-six per cent had not yet had the cause of their pain diagnosed and 60% said they had experienced barriers in accessing clear and comprehensive healthcare plans to help manage the pain. Many of the barriers were associated with cost and GP prejudice to women's pain and women's health conditions.
3. Of those women who indicated that they had experienced pain, 57% said the mismanagement of their pain had affected their professional career and 72% said it effected their personal life. Finally, 80% of those members who responded said that they had taken personal leave due to their pain.

ANMF has over 100,000 members, though the responses for the survey represent only a small number, given the strength of the response, and the number of respondents who have taken time off from work due to pain, the economic impacts of mismanaged pain are significant. The focus group participants raised the economic cost of women's pain as well, expanding this beyond reduced productivity and highlighting the impacts on women's ability to work and learn. For example, young women with undiagnosed endometriosis often have time away from school and university, interrupting their learning and subsequent career advancement opportunities. Another example is women/mothers who do not receive effective care to address conditions associated with pregnancy, for example symphysis pubis disfunction during pregnancy, or joint pain and/or painful breastfeeding post-partum, are often left with little alternative but to access personal leave or enter parental leave earlier than they have planned, resulting in ongoing budgetary impacts associated with a reduced income, extensive impacts on their personal lives and ability to socialise, and the ongoing physical and socioeconomic impacts associated with the isolation they will experience related to their pain and healthcare needs.

Comments ANMF (Vic Branch) female members made in relation to the responses they received from health professionals treating them for pain:

I have painful heavy periods I went to a male gynaecologist for this and his solution was a Mirena when I called and said there was something wrong after it was inserted I was dismissed and told it was fine it fell out not long after this and was an extremely painful situation that I feel could of been avoided if I was listened to.

I had joint pain put down to having a 'sensitive brain.' When I finally demanded a referral to a specialist, he promptly diagnosed me with inflammatory arthritis and asked why I hadn't been referred months earlier.

I have experienced endometriosis from the age approximately 16 years until a hysterectomy at 36. Only treatment initially was being put on the pill and being told to take pain relief. As years advanced was able to seek further treatment from gynaecologist.

I have chronic endometriosis, hypertonic pelvic floor, and chronic vestibular migraines. It took 14 years for my endo to be diagnosed and my pain dismissed for all those years. Only in the last 4 years have I truly felt heard and understood.

As a young girl and woman, I felt that my period pain was dismissed as something that all women get. It wasn't until I was in my 30s when I had laparoscopic surgery and was diagnosed with extensive endometriosis that my pain was taken seriously. Until then I self-medicated with NSAIDs and Panadeine to control my pain and remain functional.

Comments ANMF (Vic Branch) female members made in relation to the barriers they came up against in getting a healthcare plan for their pain condition:

Research and management of PMDD is limited, as many healthcare providers (GPs) refuse to learn more about the condition and how it affects women.

Multiple GPs did not even allow me to have a routine blood test when requested. Any pain I had was "normal for women".

Being listened to about how severe it can get. I feel like most gynaecological issues get put into one box and a very generic approach is taken and your told it will work (but it doesn't or not well).

Just brushed aside. Given analgesia but no real discussion about cause of pain or investigation of it further. Like u just need to put up with it and carry on.

Multiple investigations with lengthy time delays between getting the test done & then getting appointments to get the follow up results. Had to wait 5 months to get nerve studies done in my hometown, so had to fly to Melbourne to get them done quicker! Very costly.

The Commonwealth Governments campaign to end gender bias in healthcare says women and girls face unique challenges in Australia's healthcare system, which can lead to worse health outcomes in comparison to men, including delayed diagnosis and treatment, over prescribing and dismissal of pain.⁴ These views were all born out in the responses we received from members through the survey. In addition, focus group participants raised concerns that the poor attitudes and response to women's pain interfere with women's ability to function in their personal and professional lives. For example, one research participant discussed recent research into long COVID that demonstrated that men's complaints from the symptoms of long COVID were more likely to be taken seriously and women's were not, despite women carrying the bulk of the childcare burden. In some instances, children needed to stay with grandparents because of their mother's incapacity. Other focus group participants discussed the time and financial cost associated with the time it takes for women to access a diagnosis and comprehensive health care plan (if they do at all), noting that women often must visit multiple GPs and specialists before they even get relevant tests. In the case of the survey respondent who said it took 14 years to get an endometriosis diagnosis, considering the cost of appointments, time taken in attending appointments, and tests; the personal leave the respondent may have taken due to the impacts of the health condition and pain suffered unnecessarily; the impact of these delays could go into the thousands for one person and one

⁴ Commonwealth Government End gender bias in Australia's healthcare system <https://www.health.gov.au/news/end-gender-bias-in-australias-healthcare-system>

condition. Further, when considering the context of respondent being a nurse or midwife with some health literacy and multiplying this by the number of women with endometriosis and the average diagnosis time, the cost would be significant for this one condition. As this is repeated across so many health conditions associated with women's pain, it is reasonable to state that the health, social, and economic burden of misdiagnosis in relation to women's pain has a significant impact on the Victorian society.

Improving women's access to comprehensive pain management

It is critical, when raising the issues relating to accessing comprehensive pain management for women, that there is action to find solutions. Nurses and midwives are very well placed to be part of the solutions associated with this issue, not least because they deliver health care to people across their life span, but also because they make up the largest professional workforce in health and they predominantly have a lived experience of the problems that create barriers to women receiving quality healthcare in relation to their pain conditions.

There were four principal areas of recommendations from those people who took part in the survey and focus groups:

1. Improve women's access to diagnostics and treatment where women live. This can be through properly funded and resourced women's health services that include wrap around, multidisciplinary services like specialist physiotherapy, counselling, family violence and sexual health specialists and pregnancy care. For example, provide women access to fully funded and properly resourced (staff and equipment) self-referred nurse/midwife led women's health clinics that are part of a larger women's health hub.
2. To reduce gender bias in healthcare, increase funding for women's health research and enhance and educate medical, nursing and midwifery staff about women's health, including reviewing the curriculum for medicine to address inequity in health care. Hold ongoing forums and professional development for healthcare professionals with case studies that highlight the impact of bias and more appropriate health care professional responses.

3. Work to reduce social stigmas related to women's health and educate the community about women's health and the inequity in the treatment of women's pain, and the significant social and economic impact of the social biases that normalise or trivialise women's pain.
4. Work with marginalised groups to develop and provide additional resources to assist them to navigate and access health services, including culturally and linguistically diverse education resources for women and their families, bulkbilled health services and access to self-referral clinics. Further, it is critical that we continue to educate and hold health professionals to account for their bias towards others, whether because of their gender, cultural and linguistic background, or their psychosocial circumstances.

As discussed in the introduction of this submission, ANMF plans to organise a women's pain forum for our 90,000 female ANMF members and would extend the invitation to the Victorian Health Minister and other representatives from the Department of Health and Safer Care Victoria to provide Victoria's nurses and midwives to communicate their experiences directly to the Health Minister and to learn more about the positive initiatives that the Allan Labor Government in Victoria are providing for women and girls. Further we would be willing to share the extensive and insightful (de-identified) analysed data and comments that ANMF received from members through our survey with the Inquiry and the Women's Health and Wellbeing Program should this be requested.

Thank you again for the opportunity to make a submission to this vital inquiry that will positively impact the lives of women, girls and, by extension, the whole community. We congratulate the Allan Labor Government for this initiative and look forward to working with Mary-Anne Thomas MP, the Department of Health, and Safer Care Victoria to inform the development of effective and sensitive women's health policy in Victoria.