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Submission to senate inquiry on issues related to menopause and perimenopause

On behalf of Chronic UTI Australia, the sole national patient advocacy group for people experiencing chronic urinary tract infection (UTI), I am writing to share concerns about the increased prevalence and impact of chronic UTI on women in their peri and post-menopause years.

Our concerns that current diagnostic and treatment failures are driving increased rates of chronic UTI are detailed later in this submission. While these concerns are not limited to a specific cohort, we believe that chronic UTI particularly impacts women experiencing peri and post-menopause. The reasons for this are outlined below.

Urinary tract infections are more common in peri and post-menopausal women

Women in general are the most impacted by UTI, with 1 in 2 women having a UTI in their lifetime, compared to 1 in 20 men.¹ UTIs are common in otherwise healthy adult women, but the changes that occur during perimenopause and post-menopause increase their likelihood. When women reach perimenopause or post-menopause, typically around the age of 50, their estrogen levels decrease. Recurrent UTIs become more common at this time, as estrogen depletion alters the vaginal epithelium allowing for a more hospitable environment for UTI bacterial infection.² The change caused by this hormone deficiency has been renamed 'genitourinary syndrome of menopause' (GSM).

The changes to a woman's body because of estrogen depletion also affect the bladder and urethra, making the urinary tract more vulnerable to infection.³ Women in their later years are also more likely to experience other health conditions – such as diabetes and vaginal prolapse – that may increase the risk of UTI.

In May 2022, Dr Louise Newson interviewed Dr Rajvinder Khasriya, a urogynaecologist who heads the Lower Urinary Tract Symptoms clinic (LUTS) at the NHS (United Kingdom's National Health Service) Whittington Hospital in North London. Dr Khasriya explained how the reduced hormones in peri and post-menopause increase the likelihood of UTI's.⁴

In a recent media article in The Guardian (UK version), Professor Chris Harding, a consultant urologist at Newcastle upon Tyne Hospitals NHS Foundation, was quoted as saying:

“Vaginal oestrogen replacement has got good evidence in terms of trending UTI frequency downward and the absorption of oestrogen given vaginally is minimal so it’s pretty safe. And it’s great to have a non-antibiotic alternative to increase prevention. I sometimes use it in pre-menopausal women, too, to change the microbiological environment of the vagina.”⁵

The role of hormonal changes in peri and post-menopausal women and its impact on chronic UTI is poorly understood and managed medical professionals

Perimenopausal or post-menopausal women with an initial UTI that is not treated correctly may go on to develop recurrent or chronic UTI. Some women who have suffered for years with recurrent UTI experience an increased number and intensity of infections during this period of their lives.

Menopausal and perimenopausal women suffering with chronic UTI are impacted in several ways, as summarised below. These issues are addressed in more detail under ‘*The growing burden of chronic UTI.*’

- There is a lack of awareness amongst medical professionals and patients of menopause and perimenopause and the impacts on hormonal changes in women’s health. This includes the increased prevalence of recurrent and chronic UTI, and unfortunately many patients report having very negative experiences with healthcare providers.
- There is frequent failure to accurately diagnose chronic UTI.
- Many medical professionals do not acknowledge that chronic UTI exists, and there are no treatment guidelines. Therefore, many women experiencing chronic UTI have very limited access to healthcare for this condition.
- The debilitating symptoms of chronic UTI and lack of treatment cause severe, long-term impacts on women's quality of life. This includes but is not limited to impacts on mental and emotional wellbeing, the ability to fulfil caregiving responsibilities, personal relationships, self-esteem and social support, as well as negative economic impacts on individuals and the wider health system.

Many women have their health concerns dismissed by health professionals

In 2021, the ABC reported that more than one in three women have had their health concerns dismissed by a general practitioner (GP), based on figures from the Australia Talks National Survey 2021.⁶

Women who raise health concerns around perimenopause and post-menopause and wish to talk about hormonal therapy with their GP may find that their doctor does not want to discuss this at all, attributes their symptoms to something else, such as anxiety: often, women are not provided any treatment at all.⁷⁴ This may leave women feeling very isolated, unheard and suffering ongoing ill health.

Professor Susan David, from Monash University, recently talked to the ABC about misinformation preventing women from effective menopause treatment and called for upskilling healthcare professionals, such as GPs, in menopause and the health issues associated with the hormonal changes experienced by women in their later years.⁸ The one in three women who have severe symptoms associated with menopause are often not receiving appropriate care and can find their symptoms impact their work, caregiving responsibilities, personal relationships and life in general. Professor David noted there needs to be more research in optimising health care for women experiencing perimenopause and post-menopause.

While an increasing number of healthcare professionals and patients are becoming more educated about health issues linked to perimenopause and menopause, Professor David noted there needs to be more upskilling of medical professionals in this area of women’s health.⁹

The growing burden of chronic UTI

Chronic UTI Australia has described a growing public health crisis associated with chronic UTI, a condition that mainly (although not exclusively) affects women, including many experiencing perimenopause or post-menopause. Our concerns about the diagnosis, treatment and impacts of this condition are detailed in our *Hearing Patient Voices* survey report, which can be accessed at <https://www.chronicuti.australia.org.au/survey/>.

The report documents findings from a survey of 410 adults (396 women) experiencing chronic UTI symptoms. It adds to the increasing body of international evidence that people with chronic UTI:

- feel let down by standard UTI tests that fail to detect their infections, and antibiotic prescribing practices that both contribute to and fail to eradicate chronic, embedded infections;
- experience severe pelvic pain and other life-changing impacts of ongoing UTI symptoms;
- have great difficulty finding health care professionals who acknowledge, understand and appropriately treat chronic UTI – and are instead often dismissed, misdiagnosed and/or subject to ineffective and potentially damaging treatments; and
- are admitted to hospital and use other healthcare resources at much higher rates than the general population, creating an avoidable burden on patients and the health system.

There is mounting Australian and international data showing that complex UTI presentations are increasing at an alarming rate.¹⁰ The causes and impacts of this trend are briefly explained below.

Drivers of the crisis – poor UTI diagnosis and treatment

In Section 5 of the *Hearing Patient Voices* report, we cite some of the extensive scientific evidence on the inaccuracy of routinely used UTI tests. These standard tests are especially unsuitable for detecting infections that have become embedded in the bladder wall, as there are fewer free-floating bacteria.

New research published in *Science Advances* in November 2023, explained by Dr Jennifer Rohin, PhD, found that bacteria formed pods within the bladder wall and that current methods of diagnosing and treating these infections are inadequate, as the bacteria is embedded and is not detected in a urine sample.¹¹

Consistent with this evidence, 92.7% of our survey participants had returned a negative urine culture test while experiencing UTI symptoms. This usually meant they were denied antibiotic treatment despite having clinical symptoms and a personal history consistent with UTI. Health professionals' frequent lack of understanding that UTI tests can be inaccurate, and lack of awareness of chronic UTI, leads to misdiagnosis and ineffective, sometimes harmful, medical, and surgical treatments.

These issues were highlighted in a feature article in *The Australian* on 3 February 2024.¹²

Negative experiences of healthcare

The distress caused by chronic UTI symptoms is often compounded by health professionals' lack of understanding and ability to diagnose and treat the condition. In the *Hearing Patient Voices* report, most participants (82.6%) agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and can treat chronic UTI.

Furthermore, the survey findings included many accounts of patients being poorly treated in the health system. Some participants did report being treated with kindness, respect and understanding, but they were very much in the minority. A high proportion (81.9%) of survey participants agreed or strongly agreed that their symptoms had been dismissed or not believed by a healthcare professional. Many reported feelings of being 'belittled' by the professionals from whom they sought help.

Like the experiences of women who are perimenopausal or have already gone through menopause, chronic UTI patients often feel dismissed or not listened to by their doctors.

Further, as mentioned earlier, there is very little understanding of the connection between hormonal changes and increased risk of UTI and the potential for developing recalcitrant and persistent urinary infections.

These findings add to existing evidence that women's pain is too often dismissed or minimised by medical professionals.

Severe, long-term impacts on women's quality of life

In contrast to the frequent characterisation of UTI as a trivial and easily treated condition, people with chronic UTI suffer severe pain and quality-of-life impacts, typically for years and sometimes for decades. In the worst cases, patients become housebound, lose their livelihoods and close relationships, and see little hope for the future.

Approximately half of our *Hearing Patient Voices* survey participants rated their pain, at its worst, as 'excruciating, unbearable' (9 on a 10-point pain scale) or 'unimaginable, unspeakable' (10 on a 10-point pain scale). The average rating was 7.9 out of ten, indicating pain in the upper range between 'very intense' and 'utterly horrible.' More than 90% of participants also struggled with urinary frequency. This can be so severe that it keeps people housebound and unable to sleep.

Several participants mentioned that they had experienced serious physical health complications, such as kidney infection, sepsis, and pregnancy loss, due to untreated or poorly treated chronic UTI.

When asked to rate the effect of chronic UTI on their lives 'overall', most participants (93.7%) indicated at least a moderate impact and half (49.3%) indicated an 'extreme' impact on their lives overall. Among the 15 specific life domains we enquired about, the most heavily impacted were 'sex life', 'ability to feel good about yourself', 'mental and emotional health', 'ability to exercise', 'sleep' and 'relationship with partner'. Consistent with the severe distress caused by their chronic UTI symptoms, our participants had markedly worse mental and emotional health than age and gender matched people in the general population.

In answer to an open-ended question, one in ten participants (9.7%) volunteered — without prompting — that the condition had left them feeling suicidal or that they had planned or attempted to take their own lives because of the condition. Sadly, international chronic UTI communities are aware of several completed suicides among their members.

An avoidable burden on the health system

Menopause and associated UTI is costing the health system. In the past 5 years, in the UK there were 1.8 million hospital admissions involving UTI alone, plus even more GP appointments. The NHS says the death rate for hospital UTIs is 4 in 100, rising to 1 in 10 in those aged 95 and over.¹⁰ Chronic UTIs that are not diagnosed and therefore not treated can cause sepsis, a life-threatening condition. A quarter of all sepsis cases are related to UTI, approximately 50,000 a year in the UK. Dr Charlotte Gooding, a British Menopause Society specialist and GP in the northeast of England, found that "UTIs form a large chunk of a GPs workload in primary care and it's mostly women of menopausal age."¹³

Comparison of our *Hearing Patient Voices* survey participants in Australia with a general population sample, showed a striking pattern of much higher health service utilisation among people with chronic UTI symptoms. The differences were most pronounced for resource intensive services, such as medical specialists, hospitalisations, and emergency department visits. Participants were almost three times more likely to be admitted to hospital or to have seen three or more health professionals in the previous 12 months. While our survey data were not suitable for gauging the extent of Australian health costs due to chronic UTI, they suggest a high level of potentially avoidable expenditure.

Recommendations

Despite the growing public health crisis, accurate information about the increased risk of chronic UTI in perimenopause and menopause is not widely available to Australian women or most doctors. There are no guidelines or clear referral pathways for the significant number of women who are failed by standard primary care diagnosis and treatment for acute and recurrent UTI, and who go on to develop chronic and recalcitrant infections.

Turning the tide on this situation requires action from healthcare professional bodies, researchers and research funders, and government agencies – all in collaboration with patients and their representatives. The Australian Government has a stake in the response to chronic UTI and menopause by virtue of its interest in the health and wellbeing of Australian women, and through its funding and governance responsibility for Australian public hospitals. Chronic UTI Australia respectfully calls on the Australian Government to draw attention to the issues raised in this submission and asks it to consider responses within its remit. Priority actions could include:

- education of the public and medical professionals on menopause symptoms and treatments, include awareness of associated health impacts such as Chronic UTI. There are some good healthcare facilities in Australia who treat women with moderate to severe menopause symptoms, but many women and their doctors are unaware of the few facilities that exist;
- education on chronic UTI, for example, through publishing evidence-based, patient-centred and co-designed information about UTI in perimenopause and menopause, including issues relating to accurate diagnosis and treatment and what to do about ongoing UTI symptoms. This could build on the recently updated website of the United Kingdom's National Health Service (NHS), which has recently provided official advice on chronic UTI. The NHS webpage for UTIs now includes a section explaining that current tests do not always pick up chronic infections; that they are caused by bacteria embedding into the bladder lining; and that they require specialised treatment approaches;¹⁴ and
- funding support for one or more specialist clinics dedicated to chronic and complex UTI in Australia. Currently, unlike the United Kingdom and some other countries, there are no such clinics in Australia. Many Australian chronic UTI patients – only those who can afford it – travel to or access online consultations from the NHS' specialist UTI clinic in London. Chronic UTI Australia is in touch with researchers and clinicians, for example the Monash University and The Alfred Hospital, who would like to establish a specialist chronic UTI clinic in Australia. The availability of specialist chronic UTI diagnostics and treatment in Australia would align our healthcare system with scientific research showing that chronic UTI is a distinct condition requiring specific, evidence-based diagnostic and treatment approaches. If funded, the clinic would also provide much needed Australian research and data to improve future responses to chronic UTI.

We would welcome the opportunity to meet with members of the Senate Committee or answer any further questions. Please contact:

- myself at monica@chronicutiaustralia.org.au or on 0438-051-631; or
- Deirdre Pinto, the secretary of Chronic UTI Australia, at deirdre@chronicutiaustralia.org.au or on 0400-021-962 to arrange an in-person, online or telephone meeting.

Yours sincerely



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References

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² Rosenblum N. Update in Female Hormonal Therapy: What the Urologist Should Know: NYU Case of the Month, December 2020. *Rev Urol.* 2020;22(4):182-185. PMID: 33927578; PMCID: PMC8058921, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8058921>

³ Livescience. How estrogen fights urinary tract infections. Bhar Gholipour 20 June 2013, <https://www.livescience.com/37563-uti-estrogen-menopause.html>

⁴ Dr Rajvinder Khasriya, Dr Louise Newson Podcast 10 May 2022, <https://www.balance-menopause.com/menopause-library/unpicking-utis-and-the-role-of-hormones-with-dr-rajvinder-khasriya>

⁵ <https://amp.theguardian.com/cdn.ampproject.org/c/s/amp.theguardian.com/society/2023/dec/17/millions-of-women-are-suffering-who-dont-have-to-why-its-time-to-end-the-misery-of-utis>

⁶ One in three women has had health concerns dismissed. 7 June 2021 Stephanie Dalzell <https://www.abc.net.au/news/2021-06-07/women-health-concerns-dismissed-gender-gap-australia-talks/100188270>

⁷ I'm only halfway through my life. Midlife women are done with being dismissed. 8 August 2021 Sophie Aubrey <https://www.abc.net.au/news/2021-06-07/women-health-concerns-dismissed-gender-gap-australia-talks/100188270>

⁸ Misinformation preventing women from effective menopause treatment. ABC Interview with Professor Susan David, Monash University. 7 September 2023. <https://www.abc.net.au/news/2023-09-07/misinformation-preventing-women-from-menopause-treatment/102827170>

⁹ Ibid.

¹⁰ Data from the Australian Institute of Health and Welfare (AIHW) show that Australian UTI-related hospital admissions increased by nearly 82 percent between 1998 and 2017 (https://www.chronicutiaustralia.org.au/wp-content/uploads/2020/11/CUTI_Australia_AnnualReport_v4_Spreads.pdf). Similarly, data from the United States collected over 12 years (1998-2011) show a 52 percent increase in hospitalisations for UTI. The rate of increase was seen in both men and women but as significantly larger among women and elderly patients (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5414046>). British data show a 54 percent increase in hospital emergency department admissions for UTI between 2012 and 2016 and a 34 percent rise in diagnoses of urosepsis

(<https://amp.theguardian.com/society/2019/oct/04/rise-in-persistent-urinary-tract-infections-could-be-linked-to-antibiotics-crackdown>).

¹¹ Study uncovers potential mechanism behind chronic UTI's. Hannah Clark, 9 November 2023, Urology Times, https://www.urologytimes.com/view/study-uncovers-potential-mechanism-behind-chronic-utis?utm_source=www.urologytimes.com&utm_medium=relatedContent

¹² The article has been split into two parts): <https://www.theaustralian.com.au/science/hope-for-women-of-end-to-chronic-urinary-tract-infection-pain/news-story/2d812d507dd8c3ee204bc803d2537d5f> and <https://www.theaustralian.com.au/weekend-australian-magazine/chronic-urinary-tract-infections-why-are-doctors-only-now-waking-up-to-reality/news-story/56d1e086f805103cdb8c425a897150c4>

¹³ Women's Health, The Guardian. Kate Muir 17 December 2023
<https://www.theguardian.com/society/2023/dec/17/millions-of-women-are-suffering-who-dont-have-to-why-its-time-to-end-the-misery-of-utis>