

# Hearing Patient Voices:

CAPTURING  
THE IMPACTS  
OF CHRONIC  
URINARY TRACT  
INFECTION

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Survey Report  
**SUMMARY**

April 2023

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**This is a summary of the Survey Report, 'Hearing Patient Voices'. For a copy of the full report, please send us an email: [contact@chronicutiaustralia.org.au](mailto:contact@chronicutiaustralia.org.au)**

# DEDICATION

We dedicate this report to the late Professor James-Malone Lee, who treated and researched lower urinary tract symptoms for 40 years. He was a highly intelligent and compassionate man who truly made a difference to people all over the world who suffer from chronic urinary tract infection (UTI). He, along with our patient community, is the inspiration behind the work described in the following pages.



# ACKNOWLEDGEMENTS

**Andrea Sherwin, Marilyn Clarke-Murphy and Imelda Wilde provided valuable input to the survey questionnaire and to the written report. The project has benefitted enormously from their deep understanding of the challenges experienced by people with chronic UTI.**

We give thanks to the patient volunteers who pilot tested and provided feedback on the draft questionnaire.

We also acknowledge the volunteers around the world who manage online support groups and advocacy organisations for people suffering from chronic UTI. We are pleased that technology has enabled such groups and organisations, without which this growing patient group would remain isolated and unsupported. We are most appreciative of their support in promoting this survey to better understand the impacts of chronic UTI.

Finally, we are grateful to Community Underwriting for awarding us a grant to conduct the 'Hearing Patient Voices' survey, and to our corporate sponsors, Feel Better Box and Joode, for providing additional funds for the survey and for supporting the work of Chronic UTI Australia generally.

# GLOSSARY

- A **urinary tract infection (UTI)**, also known as cystitis, bladder infection, water infection, kidney infection or pyelonephritis, is an infection occurring anywhere in the urinary tract—from the kidneys to the urethra. A lower UTI involves the bladder and anything below, like the urethra and prostate. An upper UTI involves the urinary system above the bladder, such as the ureters and kidneys (pyelonephritis).

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- A **chronic UTI** is an embedded bacterial infection in the bladder and/or other part of the urinary tract. It is usually a result of an acute infection or series of infections that never fully went away. A chronic UTI can 'flare', which for some people feels like multiple separate acute infections. While some people feel symptom free between flares, others feel constant milder symptoms between flares. It is common for dipsticks and urine cultures to be interpreted as 'negative' with chronic UTI.

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- People with more than two culture-positive UTIs in six months, or more than three culture-positive UTIs in one year, are generally diagnosed as having **recurrent UTI**.

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- A **recalcitrant UTI** is a UTI which is difficult to treat effectively. This may be because the infection has become embedded in the bladder wall and/or because the pathogen causing the infection is resistant to the type of antibiotic used.

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- People with ongoing or intermittent UTI symptoms and negative UTI test results are commonly diagnosed with a urinary syndrome, **such as interstitial cystitis/painful bladder syndrome (IC/PBS)**. IC/PBS has long been described as a 'diagnosis of exclusion'. This means it is a diagnosis that should be given when all possible causes of ongoing LUTS have been explored and excluded, including and most especially, infection. Research shows it is impossible to exclude infection under existing testing guidelines.

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- **Lower urinary tract symptoms (LUTS)**. LUTS are a broad group of signs and symptoms that include the urgency, frequency, and incontinence of overactive bladder, voiding problems such as hesitancy and intermittency, stress incontinence, and pain, all variously overlapping.

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- **Dipstick test**. Dipsticks are often the first diagnostic tool general practitioners (GPs) use to diagnose a urinary tract infection. These tests look for signs of infection, such as white blood cells (leucocytes or pus cells), blood, pH levels and nitrites.

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- **Mid-stream urine (MSU) culture test and urinalysis**. This laboratory test uses quantitative microbial culture from a mid-stream urine sample to grow bacteria. The lab (either a real-life technician or an automated machine) will also conduct a urinalysis and look at a small amount of urine under a microscope to check for other signs of infection, such as white blood cells, red blood cells, epithelial cells, and any other signs. These readings will be used alongside the MSU culture results to determine if there is an infection.

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# SUMMARY

**This summary report presents key findings of 'Hearing Patient Voices', an online survey of 410 people with symptoms of chronic urinary tract infection (UTI). Participants were 396 women, 11 men and three non-binary/gender diverse people aged 19 – 84 years. Most lived in Australia (40.2%), the United Kingdom (28.3%) or the United States (14.3%), although many other countries were represented.**

The aim of the 'Hearing Patient Voices' survey was to understand the impacts of chronic UTI on individuals, and the potential impacts on the health system and society in general. The importance of these issues is underscored by evidence, summarised in Chronic UTI Australia's 2020-21 Annual Report ([www.chronicutiaustralia.org.au/annual-reports](http://www.chronicutiaustralia.org.au/annual-reports)), showing strong growth in hospitalisations related to UTI, and hence a growing burden to individuals and the health system.

Our participants were recruited mainly from online patient support groups. This is important to bear in mind when interpreting the survey findings, as participants were likely to have access to patient-focused information about chronic UTI that they could share with their doctors or use to find a knowledgeable health practitioner. Therefore, the rates of chronic UTI diagnosis and evidence-based treatment reported by our participants may be higher than among people experiencing chronic UTI symptoms who are not connected with patient support groups.

Four key themes emerged from the survey data: severe quality-of-life impacts; poor experiences of healthcare; diagnostic and treatment failures; and avoidable costs to the health system.

## IMPACT OF CHRONIC UTI SYMPTOMS ON QUALITY-OF-LIFE

In contrast to the frequent characterisation of UTI as a trivial and easily treated condition, survey participants had suffered serious quality-of-life impacts from their chronic UTI symptoms, typically for years and sometimes for decades.

Chronic UTI can be an extremely painful and debilitating condition. Nearly all (97.6%) of our sample reported pain as one of their chronic UTI symptoms. Approximately half of the respondents (47.8%) 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.' One participant commented:

*"The 10 in pain is not an exaggeration...it was hell I've never felt before nor anything near since."*

More than 90% of participants also struggled with urinary frequency. This could be so severe that it kept people housebound and unable to sleep.

When asked to rate the effect of chronic UTI on their lives 'overall', most participants (93.7%) indicated at least a moderate impact. 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'. For all life domains except 'managing finances', a majority of participants (more than 50%) rated the impact of chronic UTI symptoms as at least 'moderate'.

The figure on the next page lists the key themes that emerged when participants were asked to explain in their own words how their lives had been affected by chronic UTI symptoms, along with examples of participants' comments. The figure shows that 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.



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. Analysing scores on the Short Form-12, version 2 (SF-12v2®), a 12-item questionnaire about people’s health and wellbeing, we found that half of our sample had mental health component summary scores ‘well below’ the population norms and another 20% were ‘below’ the norm.

Although we were aware of these impacts before conducting the survey, it was difficult to read the countless harrowing descriptions of how participants’ lives had been derailed by extreme pain, urinary frequency and other debilitating symptoms. In the worst cases, participants were housebound, had lost their livelihoods and close relationships, and saw little hope for the future.

## EXPERIENCES OF SEEKING MEDICAL HELP

The distress caused by chronic UTI symptoms is often compounded by health professionals’ lack of understanding and ability to diagnose and treat the condition. Further, 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.

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. A high proportion (81.9%) also agreed or strongly agreed that their symptoms had been dismissed or not believed by a healthcare professional. Many reported feeling ‘belittled’ and ‘disbelieved’ by professionals from whom they sought help.

More than three quarters (76.8%) of participants agreed or strongly agreed with the statement ‘I have been given unhelpful advice to change my behaviour.’ Along with advice that was merely ill-informed (such as being told to drink more water, consume cranberry products, and sit on the toilet longer), some participants reported that health professionals had made insensitive and inappropriate comments about their (presumed) sexual practices and lack of hygiene. One participant wrote:

*‘[I] was told that I had too many sexual partners (I’ve been in a long-term relationship for 14 years) and told that I have bad hygiene – which I do not.’*

Due to the proven deficiencies of UTI tests (noted below and detailed in the report) and poor understanding of chronic UTI among health professionals, almost two thirds of participants (62.2%) had received alternative diagnoses to explain their symptoms. The most common alternative diagnoses, reported by 55.1% of participants, were 'interstitial cystitis' (IC) or 'painful bladder syndrome' (PBS). Most concerning, 17.3% had received a mental health 'diagnosis' to explain their symptoms. As we discuss in this report, attributing chronic pain or other unexplained physical symptoms to a mental health or emotional problem is alive and well in healthcare settings, despite now being widely condemned as a form of medical gaslighting.

Overall, about four in five participants had been diagnosed with chronic UTI by a health practitioner at the time they completed the survey. The other participants suspected they had a chronic UTI, based on their symptoms. The relatively high rates of chronic UTI diagnosis among our participants may reflect the fact that they had access to chronic UTI-informed doctors, as a result of information shared in online support groups. Our participants frequently commented on the difficulty they had obtaining a diagnosis before they had access to this information.

The survey findings suggested that getting a diagnosis of chronic UTI may be more difficult in Australia than many other countries. Only 72.8% of our Australian participants had been diagnosed by a health professional, compared with 83.7% of international residents. Further, 27 of the 120 Australians who had been diagnosed by a health professional had received their diagnosis overseas. Several participants commented on the high cost of accessing treatment from specialist clinics overseas and/or the long waiting times to access these overburdened services.

At the time of the survey, almost half of all participants (49.0%) said they had access to a healthcare professional who understands chronic UTI. While it is concerning that half did not have such access, even more concerning is the fact that our participants are likely to have had better access to evidence-based information and treatment than others in the community not connected with online patient groups.

## TESTING AND TREATMENT FAILURES

Most survey participants felt let down by tests used by medical practitioners to diagnose their condition. In the full version of this report, we cite some of the extensive scientific evidence on the inaccuracy of routinely used UTI tests. Consistent with this evidence, 92.7% of participants had returned a negative urine culture test while experiencing UTI symptoms. This often meant they were denied antibiotic treatment despite having clinical symptoms and a personal history consistent with UTI. The following quotes are typical:

*"[I've] been told it was all in my head as I returned a negative test result."*

*"[I was portrayed as] someone who may be addicted to pain medication claiming to be in excruciating pain despite having negative UTI results."*

*"I...would not be given antibiotics without an infection showing in urine so I was diagnosed with Interstitial Cystitis."*

Many participants reported that health professionals' frequent lack of understanding that UTI tests can be inaccurate, and lack of awareness of chronic UTI, had led to misdiagnosis and ineffective, potentially harmful, medical, and surgical treatments. More than two thirds of participants (67.1%) had been offered or given therapies they believed were inappropriate and/or unhelpful. These were not only ineffective in most cases, but could be invasive, have unpleasant and sometimes irreversible and harmful side effects, cause pain, exacerbate symptoms, and be expensive.

While about two thirds (64.4%) of our participants had been told by a healthcare professional that nothing could be done for their symptoms, the scientific literature contains evidence that chronic, embedded infections can be cleared through the continuous use of full-strength antibiotics – often for a protracted period. In our survey, participants undergoing this form of treatment were significantly more likely than others to report that their chronic UTI symptoms were improving.

Despite chronic UTI being a treatable – albeit challenging – condition, the survey findings demonstrate the difficulties of accessing effective treatment. Participants who received antibiotics often did so only intermittently or at low (prophylactic) doses. 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.

The survey highlights the need for appropriate diagnosis and treatment of acute and recurrent UTI, with the expectation that this will reduce the risk of infections becoming embedded and chronic. Several participants expressed a view that too short and/or intermittent courses of antibiotics had contributed to the development of their chronic UTI.

Although a few participants appeared to have developed chronic UTI after a single infection, on average there was 8.5 years between participants' first UTI and the onset of persistent symptoms indicating a chronic UTI.

There is, therefore, potentially a substantial window for proper treatment and prevention of acute and recurrent UTI, which may help reduce the risk of symptoms becoming persistent or chronic.

Once an infection has become chronic and embedded, it is essential that the person is able to access evidenced based, sustained and affordable treatment. In our survey, many participants commented on the difficulty of getting access to the protracted antibiotic treatment their infections required, often because their doctor admitted to being worried about falling foul of policies designed to limit antibiotic prescribing.

While strongly endorsing patient access to the most effective chronic UTI treatment currently available, Chronic UTI Australia also advocates for urgently needed research to develop better alternatives. We note that several survey participants expressed concern about having to take long-term antibiotics, with some mentioning physical health problems, such as digestive issues, they believed had been caused or exacerbated by antibiotics.

## COSTS TO THE HEALTH CARE SYSTEM

Chronic UTI is causing avoidable costs to the health care system. Comparison of our participants 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 health costs due to chronic UTI, the results suggest a high level of potentially avoidable expenditure.

## CONCLUSION

Chronic UTI is one of several health conditions predominantly affecting women that are traditionally neglected in medical research and practice. While conditions such as endometriosis and pelvic mesh injury are finally getting the attention they deserve, chronic UTI remains poorly recognised and treated.

Chronic UTI is a significant women's health condition and an under recognised and under diagnosed cause of persistent pelvic pain.

Sufferers of chronic UTI are more likely to access resource intensive medical services such as specialists and hospitalisations, and receive misdiagnoses, unnecessary invasive tests and inappropriate treatments.

People with chronic UTI endure distressing life altering symptoms that can persist for many years, even decades. Collectively, they describe harrowing experiences of unacceptably poor treatment within the health system and feelings of neglect, being dismissed, belittled or not believed by health professionals.

Most people surveyed had mental health and wellbeing scores below those of the general population, and of great concern, one in ten disclosed having suicidal thoughts.


The apparent lack of chronic UTI knowledge among healthcare providers has led to many sufferers being forced to seek a diagnosis and treatment from specialist clinics abroad.

Through this patient survey, Chronic UTI Australia is raising critical awareness of this neglected health condition and the detrimental impact it has on those who suffer, mostly in silence.


To turn the tide, education is needed among healthcare professionals and the public—especially high-risk groups such as young women. We must ensure there is communication and positive engagement between patient groups, health professionals, researchers and policy makers. Dedicated chronic UTI specialists must be introduced to pelvic pain clinics Australia-wide, and significant funding for applied and translational UTI research must be given the highest priority to stem this growing public health problem.


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