Chronic UTI Worksheet

CHRONIC Australia Inc.

Symptoms, signs and information to share with your doctor

Welcome to the Chronic UTI Worksheet

Thank you for downloading the Chronic UTI Worksheet. This document will help you recognise chronic UTI symptoms that are often missed, overlooked and wrongly attributed to something else. The worksheet will also help you understand why symptom recognition is crucial in the diagnosis of chronic UTI and in managing treatment.

How to use this document

The Chronic UTI Worksheet is for anyone who thinks they may have a <u>chronic UTI</u>. It is designed for you to print and complete the questions at home, or together with your doctor during a scheduled long appointment. The questions and the symptom checklist provide information to help your doctor formulate an initial diagnosis. The Question Set for Chronic UTI (see <u>page 7</u>) is used to log chronic UTI symptoms. It has been scientifically validated¹⁻³ to use at the first appointment, as well as subsequent appointments to help monitor your response to treatment.

Why symptoms are important when diagnosing chronic UTI

A chronic UTI is harder to diagnose on routine tests as the bladder wall is colonised by embedded bacteria. In all types of UTI, especially chronic UTI, the diagnosis can be missed when using a dipstick or urine culture. However, if a fresh microscopy examination of urine is performed, it will often show white cells (pus) and epithelial cells (cells shed from the bladder lining). MSU culture may grow more than one bacterial species and be dismissed as mixed growth of doubtful significance, contamination or no significant growth. Checking pus and epithelial cell counts on fresh, unspun microscopy helps to monitor response to treatment. To understand more about problems diagnosing UTI, please visit our website, including our 'UTI Testing' page: www.chronicutiaustralia.org.au/uti-testing/

Since suitable tests to diagnose chronic UTI do not exist, and standard tests miss this type of infection, researchers in the UK came up with a reliable method to diagnose chronic UTI by focusing closely on a person's symptoms using validated symptom scores, along with their UTI history and signals found on fresh, unspun urine microscopy (pus and epithelial cells). The researchers tested and retested these methods and then applied them to thousands of people attending a specialist UTI clinic to help diagnose the infection and manage treatment. ¹⁻³ Researchers are now working to advance the technology using artificial intelligence so that diagnosis and treatment management is quicker, performed at the bedside during a consult, and is widely accessible to clinicians and patients all over the world—leading to earlier diagnosis and treatment. We look forward to these developments.

¹link.springer.com/article/10.1007/s00192-018-3569-7

² pubmed.ncbi.nlm.nih.gov/28971220 ³ pubmed.ncbi.nlm.nih.gov/18206957

Additional resources for your doctor

The final section of the worksheet includes useful resources to share with your doctor so you can both gain a better understanding of chronic UTI. You can choose articles to print and share with your doctor or you can share the full list of URLs for your doctor to follow up.

Tips for preparing to speak with your doctor:

- 1 Collect previous copies of your UTI test reports.
- 2 Educate yourself on chronic UTI.
- Prepare for your appointment (complete worksheet, make notes etc).
- Join the global chronic UTI community and an online support group.
- Be proactive, positive and persistent.
- Visit the 'What to do if you think you have a chronic UTI' page on our website for more information about preparing for an appointment with your doctor to discuss chronic UTI.
 www.chronicutiaustralia.org.au/chronic-uti/what-to-do-if-you-think-you-have-a-chronic-uti/
- The Better Health Channel also shares helpful tips on how to prepare for an appointment with your doctor.

 www.betterhealth.vic.gov.au/health/servicesandsupport/seeing-a-doctor-or-general-practitioner#making-an-appointment-with-a-doctor



What are your symptoms? (what you feel)

For help with understanding symptoms, please see the 'Question Set for Chronic UTI' on page 7.

1.	Do you experience pain? E.g. stinging with urination (dysuria), filling bladder pain, urethral pain, dull pelvic pain, kidney/flank pain etc. See page 7 for more examples.	Yes No List symptoms here:
2.	Do you experience voiding symptoms? E.g. reduced stream, intermittent stream, straining to void, hesitancy etc. See page 7 for more examples.	Yes No List symptoms here:
3.	Do you experience stress urinary incontinence? E.g. from coughing/sneezing, laughing, exercise etc. See page 7 for more examples.	Yes No List symptoms here:
4.	Do you experience an over active bladder? E.g. urgency, frequency, nocturia, running water urge incontinence, premenstrual aggravation etc. See page 7 for more examples.	Yes No List symptoms here:



5. Do you experience other non-specific UTI symptoms?

E.g. fatigue, headaches, brain fog, loss of balance, falls, poor memory, thigh or leg pains, low grade fevers, sensory symptoms, anxiety and worsening of mental health conditions and anything else specific to you.

Yes		No
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List symptoms here:

Symptoms indicating your infection has become serious:

- · Nausea or vomiting
- Temperature above 38°C
- Shivering/chills and rigors
- Muscle pain
- Feeling confused or very drowsy
- Not passing urine all day
- Kidney pain/loin pain (pain in the upper back on the right or left or beneath the ribs)
- · Blood in the urine
- Worsening UTI symptoms while taking antibiotics
- No improvement in UTI symptoms after 48 hours of antibiotic treatment

IMPORTANT: If you are experiencing any of these symptoms, please seek urgent medical care. It could mean your infection has become much more serious

6. Where do you feel your symptoms?

Please circle using the 'draw tool' or print and circle:



7. Overall, how do you rate your physical pain?

Please circle using the 'draw tool' or print and circle the face that best depicts the pain you are experiencing:



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Originally published in Whaley & Wong's Nursing Care of Infants and Children. ©Elsevier Inc. Wording modified for adult use.

8. List your most difficult symptom/s and explain the impact this has on your personal life.

E.g. emotional impacts like feeling embarrassed or ashamed, loosing self confidence, changes in mood and mental health—physical impacts like being unable to travel short or long distances, care for family, perform in your job/studies, be intimate and maintain relationships and what have you changed to cope?

Explain the impact here:



Are your symptoms constant or intermittent?	Constant Intermittent
 10. When did your symptoms start? Was there an incident or a trigger? E.g. after an acute UTI, after child birth, after a pelvic operation, after becoming sexually active or entering a new relationship, after catheter insertion in hospital, after a holiday etc. 	Explain here: No incident I can think of (tick if it applies)
11. What helps make your symptoms better? E.g. prescribed antibiotics, anti-inflammatory medication, any self directed, over-the-counter medication such as d-mannose and ibuprofen, increasing or restricting fluid intake, any medical or surgical interventions that helped alleviate symptoms.	Explain here: Nothing helps (tick if it applies)
What makes your symptoms worse? E.g. sexual intercourse, drinking alcohol, exercise, stress, certain foods, ovulation, menstruation, menopause, any medications, examinations, surgical procedures etc.	Explain here: Nothing (tick if it applies)
47.6: 11:1	
13. Since this began, are your symptoms getting better, worse or staying the same?	Better Worse Same
14. If you had a UTI test recently in a healthcare setting, what was the result (as determined on urine testing by your health practitioner)? There are more questions about UTI tests in the next section.	Urine dipstick: Positive for UTI Negative for UTI Urine culture: Positive for UTI Negative for UTI Any other comments about your test results:



Signs/signals (what can be seen or measured by you or your doctor)

15. If you use dipsticks at home, do you notice UTI markers showing? E.g. leucocytes/white blood cells, blood, nitrites, etc. (Make sure to follow the correct timing instructions for dipsticks.)	To do: Take a picture and bring to your appointment if appropriate. Done
16. Do you have any urine culture reports? Pay attention to any comments on the report that could indicate chronic infection, even if the culture test is reported as 'negative'—urine microscopy (white cells or leucocytes, epithelial cells, blood, casts), no significant growth, mixed growth of doubtful significance, light growth of probable contaminants, no growth etc.	To do: Collect copies of your UTI test report, mark any suggestions of chronic infection with a highlighter and bring to the appointment. Done
17. Do you notice blood with or without clots seen in your urine? Do you notice cloudy urine with or without lots of particles? Do you notice strong or foul-smelling urine?	To do: Collect a sample of your urine in a specimen container and take a picture or bring it to the appointment. Done
18. Have you noted discomfort on your lower belly just above pubic bone or in the right or left kidney area? Do you have pain on pressing the above areas?	Your doctor can feel for this.
19. Do you have any fresh urine microscopy results (sought independently or performed at home) identifying signs of infection like white blood cells (pus) and epithelial cells?	To do: Bring report or take a picture and show your doctor. Done



UTI History

20. Have you had acute UTIs previously?	Yes No
21. When did your UTIs first start?	Explain here:
22. How many 'positive' acute UTIs have you had in the past year (as determined on urine testing by your health practitioner). Include how many of these were treated with antibiotics and for how long?	1 2 3 4 5 6 7 8 9 10+ Add comments here:
23. Did you notice a time when your UTI tests changed from 'positive' to 'negative' (as determined on urine testing by your health practitioner) despite having UTI symptoms?	Yes No If yes, please explain:
24. Describe any previous treatments and how your symptoms responded to each of them.	Explain here:

Question Set for Chronic UTI



The Question Set for Chronic UTI was developed by Professor James Malone-Lee through several decades of research studying and treating thousands of patients in his UK clinics. The NHS Lower Urinary Tract Symptoms (LUTS) Service and the private Artemis Cystitis Clinic, both in London, run through the full question set at each appointment—at the first appointment to assist in forming an initial diagnosis, and then at subsequent appointments to monitor treatment.

The results are scored using the instructions provided and then charted on a graph. Symptoms generally oscillate and the validated symptom set below will provide an overview regarding their progress. You and your doctor can use the checklist in the same way to follow your own progress.

Name:

Instructions

Yes responses = 1 point No responses = 0 points

Daytime and nighttime frequency events and incontinence episodes are also important symptoms to monitor and are recorded separately to assess the degree of bother and inconvenience to activities of daily living (ADL) and quality of life (QoL). Patients are also asked how they are now compared to their most recent visit and their first visit (worse, no change, mildly, moderately, much better or cured).

Storage Symptoms		
1. Urgency	Yes No	
2. Urgency incontinence	Yes No	
3. Latchkey urgency	Yes No	
4. Latchkey urge incontinence	Yes No	
5. Waking urgency	Yes No	
6. Waking urge incontinence	Yes No	
7. Running water urgency	Yes No	
8. Running water urge incontinence	Yes No	
9. Cold urgency	Yes No	
10. Anxiety urgency	Yes No	
11. Premenstrual aggravation	Yes No	
Storage Symptom Tally =		

Today's Date:

Stress Sympton	ns	
12. Cough/sneeze incontinence	Yes No	
13. Exercise incontinence	Yes No	
14. Laughing incontinence	Yes No	
15. Passive incontinence	Yes No	
16. Bending incontinence	Yes No	
17. Standing incontinence	Yes No	
18. Lifting incontinence	Yes No	
19. Pre-cough preparation	Yes No	
Stress Symptom Tally =		
Voiding Symptor	ns	
20. Hesitancy	Yes No	
21. Reduced stream	Yes No	
22. Intermittent stream	Yes No	
23. Straining to void	Yes No	
24. Terminal dribbling	Yes No	
25. Post-void dribbling	Yes No	
	Yes No	

Symptom Tally =

Pain Symptoms		
27. Suprapubic pain	Yes	No
28. Filling bladder pain	Yes	No
29. Voiding bladder pain	Yes	No
30. Post-void bladder pain	Yes	No
31. Pain relieved by voiding	Yes	No
32. Partially voiding relief	Yes	No
33. No voiding relief	Yes	No
34. Loin pain	Yes	No
35. Iliac fossa pain	Yes	No
36. Pain radiation to genitals	Yes	No
37. Pain radiation to legs	Yes	No
38. Dysuria	Yes	No
39. Urethral pain	Yes	No
Pain Symptom Tally =		
Overall Symptom Tally =		

Further information and important links



Chronic UTI information that can be shared with your doctor

- Chronic UTI Australia website www.chronicutiaustralia.org.au
- 2. Chronic UTI picture commentary developed by Professor James Malone-Lee https://www.chronicutiaustralia.org.au/wp-content/uploads/2018/08/00-Chronic-urinary-infection-Picture-Commentary-August-2018.pdf
- 3. Cystitis Unmasked by Professor James Malone-Lee (2021) www.tfmpublishing.com/cystitis-unmasked
- 4. Confronting the urinalysis tyrant, BJGP Life (2021) www.bjgplife.com/confronting-the-urinalysis-tyrant/
- 'Battler's disease': UTI sufferers' plight relegated by medicos, The Weekend Australian Magazine www.chronicutiaustralia.org.au/wp-content/ uploads/2024/04/The-Weekend-Australian.3Feb2024.pdf
- Chronic UTIs and test flaws overlooked in 'archaic' guidelines: urologists, Australian Doctor News www.chronicutiaustralia.org.au/wp-content/ uploads/2024/04/230224-AusDoc-cUTI.pdf
- 7. 'Aussie women struggling to have chronic UTI treated', The Project (2024) www.youtube.com/watch?v=OGpGs6wpXMM
- 8. 'Agony and the urge to pee: the growing evidence giving hope to chronic UTI sufferers' (2024) www.theguardian.com/australia-news/article/2024/jun/02/agony-and-the-urge-to-pee-the-growing-evidence-giving-hope-to-chronic-uti-sufferers
- 9. Professor James Malone-Lee's Australian interview on chronic urinary tract infection (2021) www.youtube.com/watch?v=5RmbLcXKMvI&t=166s
- Urinary Tract Infections: 3 facts about UTIs you MUST know (2023) <u>www.youtube.com/watch?v=OGOfF-2oYdU</u>
- 11. 'Hearing Patient Voices' chronic UTI quality-of-life survey report (2023) www.chronicutiaustralia.org.au/wp-content/uploads/2023/05/Hearing-Patient-Voices-Survey-Report.2023.pdf
- 12. Urinary Tract Infection factsheet (2024)

 www.chronicutiaustralia.org.au/wp-content/
 uploads/2024/02/The-Urinary-Tract-Infection-UTIFactsheet-February-2024.pdf
- 13. MJA Insight article (2024) <u>insightplus.mja.com.</u> <u>au/2024/30/its-time-we-recognised-chronic-urinary-tract-infection/</u>

More information

www.chronicutiaustralia.org.au

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Chronic UTI Australia has permission to include the following:

- The Question Set for Chronic UTI as used by the NHS LUTS Service at Whittington Hospital, London and the Artemis Cystitis Clinic, 10 Harley Street, London.
- Wong-Baker FACES® Pain Rating Scale (FACES Scale).