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 to use at the first appointment, as well as subsequent appointments to help monitor the 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. The current gold standard tests to diagnose UTI (dipstick and MSU culture) are not validated to diagnose a chronic UTI. Unlike acute UTI, chronic UTI patients reveal a low number of white cells (pus), high epithelial cell counts and overall less bacteria counts. They may show more than one bacteria on the MSU culture and be dismissed as having mixed growth of doubtful significance, contamination or no significant growth. Monitoring the pus and epithelial cell counts on fresh, unspun microscopy is important during chronic UTI treatment. To understand what all this means, please read more on 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 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

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:

- 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

1



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 gradefevers, sensory symptoms, anxiety and worsening of mental health conditions and anything else specific to you.

| | Yes | | No |
|--|-----|--|----|
|--|-----|--|----|

List symptoms here:

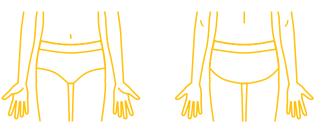
Symptoms indicating your infection has become serious:

- · 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. physical and emotional impacts such as embarrassment, loss of self confidence, ability to travel short and long distances, ability to care for family, job performance, impact on intimacy and relationships, mood and mental health. What do you do to try and overcome these and what adaptations have you put in place to cope?

Explain the impact here:



| 9. 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) |
| 12. 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) |
| 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 up? 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:

Today's Date: _____

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).

| St | orage Sympto | oms | |
|-----|---------------------------------------|-----|----|
| 1. | Urgency | _ | 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 |
| | orage mptom Tally = | | |

| 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 = | |
| | ns |
| Symptom Tally = | ms Yes No |
| Symptom Tally = Voiding Symptom | |
| Symptom Tally = Voiding Symptom 20. Hesitancy | Yes No |
| Symptom Tally = Voiding Symptom 20. Hesitancy 21. Reduced stream 22. Intermittent | Yes No |
| Symptom Tally = Voiding Symptom 20. Hesitancy 21. Reduced stream 22. Intermittent stream | Yes No Yes No |
| Symptom Tally = Voiding Symptom 20. Hesitancy 21. Reduced stream 22. Intermittent stream 23. Straining to void 24. Terminal | Yes No Yes No Yes No Yes No |
| Symptom Tally = Voiding Symptom 20. Hesitancy 21. Reduced stream 22. Intermittent stream 23. Straining to void 24. Terminal dribbling 25. Post-void | Yes No Yes No Yes No Yes No Yes No |

Symptom Tally =

| Yes | No |
|-----|---|
| Yes | No |
| | |
| | |
| | Yes |

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 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/
- 5. '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=5RmbLcXKMvl&t=166s
- 10. Urinary Tract Infections: 3 facts about UTIs you MUST know (2023) www.youtube.com/watch?v=OGOfF-2oYdU
- 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

Produced by Chronic UTI Australia (Inc.)

Reviewed and edited by Dr Sheela Swamy, PhD MRCOG, consultant in obstetrics and gynaecology at Guys & St Thomas NHS Foundation Trust with special interest in urogynaecology and chronic UTI, women's services UGME lead and joint wellbeing lead, Kings College London, stage 3 women's health block lead, clinic lead at Artemis Cystitis Clinic, 10 Harley Street, London, UK.

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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).