The women behind the fight for chronic UTI recognition after years of suffering

MPs will be gathering in Parliament for a landmark debate on chronic UTI

(Left to right) Pheobe Price, a patient, Caroline Sampson, a patient, Rajvinder Khasriya, a doctor, Vicky Matthews, a patient, Joanne McKinlay, a campaigner, and Sarah Heaton, a patient

Connie Dimsdale
Education and News Reporter
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For years, countless women have been suffering from daily agonising bladder pain.

Patients' lives have been ruined by a condition they thought was nameless, doctors have misunderstood their symptoms, and scientists have been struggling to understand the hidden health crisis.

This all changed with Professor James Malone-Lee, a pioneering doctor behind the diagnosis and treatment of chronic urinary tract infections (UTI).

After his death in 2022, his legacy can be seen in a limited number of clinics now treating the condition, a charity and a Facebook patient support group with 27,000 members, who have been lobbying the NHS and Government for change.

Finally, MPs will be gathering in Westminster Hall on Wednesday morning for a landmark Parliamentary debate on chronic UTI.

Here, we'll take a look at the journey so far and some of the key figures behind the long fight for better treatment and research into chronic UTI.

The patients: 'We're still trapped in pain'

Despite huge steps forward, including new treatment methods and the recognition of the condition's existence by the UK health authorities, many sufferers are still stuck in pain.

Vicky Matthews, who has been suffering for 24 years and was finally diagnosed in 2019, said patients are fighting an "uneducated" healthcare system that is not set up to support them.

"I'm calling on our Government to recognise the importance of the debate and use it as a catalyst for change," said Ms Matthews, 45, from the Wirral. "Because thousands of women are trapped in pain and trapped in the system that denies their illness."

(Left to right) Caroline Sampson, 61, Vicky Matthews, 45, and Phoebe Price, 24, all suffer from a chronic UTI

Sufferers have clubbed together to lobby the Government, including Phoebe Price, 24, from South London, and Sarah Heaton, in her thirties, from West Yorkshire.

Ms Price wrote to her MP, the Liberal Democrat Luke Taylor, who is leading Wednesday's debate, in November 2024 to highlight the condition.

She said that securing a parliamentary debate was "a huge step forward" for patients

"It's also a testament to the strength of our community, who have campaigned relentlessly for change despite immense suffering," she said.

The debate gives the community "hope", which has been in "short supply" after some members have tragically taken their own lives, Ms Heaton said.

"It finally puts our condition on the map, and it finally validates our suffering."

For patients who cannot tolerate the main form of chronic UTI treatment of long-term, narrow-spectrum antibiotics, everything is riding on further research into the disease.

"It is absolutely soul-destroying to live with a chronic UTI, and to no longer tolerate antibiotics due to all the dreadful side effects," said Caroline Sampson, 61, from Hertfordshire. "The infection has completely derailed my life in all possible ways."

The doctors and scientists: 'We were ridiculed'

Doctors and scientists have been researching and treating chronic UTIs for nearly 20 years, long before it was recognised as a condition and respected in the scientific community.

Leading NHS urogynaecologist Miss Rajvinder Khasriya, who started doing a PhD with Prof Malone-Lee in 2007, said her team was "frequently ridiculed and attacked in conferences" when they first started discussing the condition.

Now, she runs the Lower Urinary Tract Symptoms (Luts) Service at the Whittington Hospital, which is the only dedicated NHS chronic UTI treatment centre in the country with a waiting list stretching over a year.

She described the debate as "a really important step forward in changing this situation by bringing focus to it, hopefully from the health department".

Several other doctors have been integral to the fight, including Dr Catriona Anderson, who runs a specialist clinic in Staffordshire and Mr Sachin Malde, a consultant urological surgeon based at Guy's and St Thomas' Hospital in London.

Dr Anderson said that although significant progress has been made, we are "still not meeting ideal diagnostic and treatment aims in this patient population who are long-suffering".

(Left to right) Dr Catriona Anderson and Professor Jenny Rohn have made huge contributions to the field

Scientists have also made huge contributions to progress with research into why chronic UTI happens, new diagnostic methods and more effective treatment options.

Professor Jenny Rohn, a microbiologist specialising in UTI at University College London (UCL), said the Parliamentary debate is “long overdue” after “many years of people fighting to get any recognition for this problem”.

She started studying chronic UTI in 2011 when research was “frankly non-existent” and has since published peer-reviewed research into how bacteria hide inside the bladder lining and cause a chronic infection.

The campaigners: ‘Everyone deserves a pain-free life’

Patients who have been severely affected by chronic UTI have been fighting tirelessly to advocate for life-changing chronic UTI.

So far, the NHS has officially recognised that the condition exists, adding to its online information for patients, and the National Institute for Health and Care Excellence (Nice) has recognised it as unique from recurrent and acute infections.

But Nice has still not agreed on specific guidelines for diagnosis or treatment, meaning it’s “almost impossible for patients to get a correct diagnosis or to be referred by their GP for effective treatment”, according to the charity CUTIC (Chronic Urinary Tract Campaign).

(Left to right) Campaigner Joanne McKinlay and the co-directors of CUTIC, Carolyn Andrew and Alison Pearce

“There is no training in chronic UTI to newly qualified doctors, and many patients are living their lives in agony and despair,” charity co-directors Carolyn Andrew and Alison Pearce added.

Sufferer-turned-campaigner, Joanne McKinlay, has also dedicated her life to raising awareness for chronic UTI, setting a Facebook support group for people who have been misdiagnosed and gaslit by the medical profession.

“Our community is incredibly strong and supportive, and I am immensely proud of everyone who has contributed to this movement despite battling this condition themselves,” Ms McKinlay said.

“Every person deserves a life free from pain and with improved first-line care, this vision is within reach,” she added.

The politicians: ‘Healthcare is failing women’

Sutton and Cheam MP Taylor said that the nation’s healthcare system is a “story of failure” for chronic UTI sufferers.

The last time chronic UTI was debated in Parliament was an adjournment debate in 2016 led by Labour MP Catherine West.

Taylor said the debate is set to call for practitioners to be educated about chronic UTI and for “proper funding into research around future treatments”.

“That’s how we can give hope to these brave sufferers,” he added.

The Government said its efforts to cut the NHS waiting list and deliver extra appointments will benefit sufferers of conditions like chronic UTIs.

It is also funding, through the National Institute for Health and Care Research, further research “to improve the diagnosis and treatment of urinary tract infections (UTIs)”.

A spokesperson said: “Living with a chronic UTI can be extremely debilitating, and patients should receive compassionate care and support from the NHS.”

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