World Bladder Cancer Patient COALITION

# What nobody tells you:

## An opinion piece on bladder cancer, continence and the care that is missing




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## An opinion piece on bladder cancer, continence and the care that is missing

Bladder cancer affects the very organ responsible for storing urine and controlling when and how we pass it. So it should come as no surprise that many people living with this disease face real challenges with bladder and bowel control. And yet this is one of the last things that gets talked about, in clinics, in research and in public.

This World Continence Week (June 15-21, 2026), we asked a urologist, a nurse researcher and a patient to each answer the same question: ***why is continence still the conversation bladder cancer care refuses to have?*** Their answers, from the operating table, the clinic and the patient community, tell a story worth hearing.

### *"Patients deserve to know what is coming"*

Continence problems in bladder cancer are not rare, and they do not look the same for everyone. They depend on the type of cancer; the stage of treatment and the choices made along the way.

For most people diagnosed with bladder cancer, the disease is caught before it has spread into the muscle wall. This is called non-muscle-invasive bladder cancer (NMIBC), and it accounts for **roughly three in four diagnoses**. Treatment involves surgery to remove the tumour, often followed by a course of treatments delivered directly into the bladder, most commonly BCG immunotherapy.

These treatments work, but they also irritate the bladder tissue. Many patients experience a frequent, urgent need to urinate, disrupted sleep from waking at night, and sometimes leakage. For some, these symptoms last for years, running quietly alongside their surveillance appointments and their daily lives.

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**People are diagnosed with bladder cancer every year worldwide**

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For those whose cancer has grown deeper into the bladder wall, treatment is usually more radical. Removal of the bladder (radical cystectomy) is often the recommended option, after which urine needs a new route out of the body. Surgeons create this using a small section of bowel, and this affects more than just urinary continence. Bowel function can take months to settle. Where radiotherapy is used, it can bring additional challenges, including urgency, diarrhoea and lasting changes to the bladder and bowel lining. These are significant, life-changing consequences, and they deserve to be part of the conversation from the very beginning.

*"If we do not tell patients what is coming, we cannot honestly say we gave them a real choice,"* says Prof Shingai Mutambirwa, Head of the Department of Urology at Dr George Mukhari Academic Hospital and Sefako Makgatho Health Sciences University in South Africa, and member of the Continence Association of South Africa.

*"A real conversation about surgery means explaining what continence will look like afterwards, what recovery involves, and what support will be there. Without that, we are not truly sharing the decision with the patient."*

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This matters everywhere, but it matters most where specialist support is hardest to access. 614,298 people are diagnosed with bladder cancer every year worldwide, the majority of them in countries where there are simply not enough urologists to provide the depth of guidance that these decisions require. Good continence care after bladder cancer is not just a clinical standard to aspire to. It is a question of fairness.

### *"We know what makes a difference. We just need to start earlier"*

There is strong and growing evidence that preparing people well before major surgery leads to better outcomes afterwards. This is called prehabilitation, and it covers physical fitness, nutrition and psychological readiness. It also, crucially, includes preparing the body and mind for what continence will mean after surgery.

Urology nurses have been at the heart of this work for decades. They are often the first person a patient speaks to after diagnosis, and the most consistent presence throughout treatment. This puts them in a unique position to have the conversations that matter, including asking about bladder symptoms, providing honest information about what surgery will mean, teaching pelvic floor exercises before an operation, and making sure patients know what to expect when they go home.



**In Denmark, a structured programme to prepare patients before bladder removal, was tested in a clinical trial and then adopted as standard practice.**

The results showed real improvements in how patients recovered. But this kind of programme is still the exception, not the rule, in most parts of the world.

*"Prehabilitation is not something reserved for the best-resourced hospitals,"* says Prof Bente Thoft Jensen, Clinical Nurse Specialist and Senior Researcher at Aarhus University Hospital in Denmark, Section Leader in Prehabilitation at the National Centre of Research in Cancer Surgery (ACROBATIC), and Chair of the EAUN Bladder Cancer Special Interest Group. *"It is about changing when care begins. Continence cannot keep being treated as a problem that appears after surgery and gets passed on to someone else. It needs to be part of the plan from day one."*

Good written and verbal information also plays a fundamental role. Too many patients decide on major surgery without having been given clear, honest, accessible information about what their bladder and bowel control will look like afterwards.

Guidelines and nursing standards exist, but they are not applied consistently. Investing in urology nursing is not just a workforce question. It directly shapes whether patients recover well or struggle alone.



## *"We talk about it with each other, because we rarely get to talk about it with our doctors"*

Alessandro Boni was diagnosed with non-muscle-invasive bladder cancer in 2018. Over the three years that followed, he went through surgery and a full course of BCG treatment. The clinical team focused on the tumour. What nobody talked about was what was happening to his bladder in the process.

*"The practical impact of surgery and therapies is often invisible to the medical record but not to the person living it. The first reaction those frequent cases of cystitis for instillations is to buy diapers in-hiding at the supermarket, but since then daily life has changed,"* says Alessandro, PaLiNUro (Italy) and WBCPC Board Member. *"You have to memorise every public bathroom. You stop accepting invitations to places where you cannot be certain of logistics. Then you stop bringing it up because you feel like you should just be glad to be alive. But living with that quietly, without any support or even any indication of how, for example, to strengthen the pelvic floor, takes a toll."*

In the patient community Alessandro is part of, both in Italy and across Europe, this experience is extremely common. For people managing NMIBC, urgency and frequency become background noise that they carry privately.

*"You have to memorise every public bathroom. You stop accepting invitations to places where you cannot be certain of logistics"*

For those who have had their bladder removed and are living with a neobladder, the adjustment is even more complex. The impact on relationships and intimacy is real in those cases. The anxiety and loss of confidence are real. And the shame that many people still feel around incontinence, in every culture and at every age, too often stops them from seeking help that could be available to them.



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*"I listened to many patients with neo bladder and I learnt that people living with a neobladder face a different learning curve, and often face it alone"* Alessandro says *"For this type of patient, learning to urinate by feel – through abdominal pressure is something that takes months, if no one has said to them in advance about what and how they can do to manage it.*

*Others have spoken about the disconnect between being told the surgery was a success and the reality of rebuilding an entirely new relationship with their own body. "I was grateful to be alive," one person told me. "But I had no idea how much I would have to relearn for my rehabilitation, and no one to ask."*

Another thing to be considered is the difference in post-surgery between men and women and the importance of reconsidering the consequences in continence before the surgery or to evaluate different way to make cystectomy also thinking to maintain a certain quality of life in that sense as well.

The WBCPC's global patient and carer experience survey has shown clearly that quality of life, continence and mental wellbeing are among the biggest unmet needs for people living with bladder cancer around the world. Patients already know this. It is time for health systems to catch up.

*"Most people are not angry. They are just surprised,"* says Alessandro. *"They say: no one told me this would happen. No one asked how I was coping. No one gave me the real perspective. That is where it starts, with someone deciding this conversation is worth having."*

What the patient community is asking for it is not extraordinary. We want bladder cancer follow-up visits to include a standing question about continence, not optional, not triggered only by complaint, but routine.

**400 million**
**people affected by incontinence globally**

We want the healthcare professionals who see us to have a name for what we are experiencing and a pathway to offer. And we want public campaigns that normalise this conversation, so that the first time a person with bladder cancer tries to describe their symptoms, they do not have to overcome shame before they can ask for help.

## Our call to action for World Continence Week 2026

Incontinence affects more than 400 million people globally. It carries stigma in every country and every culture, and that stigma too often stops people from asking for help. For the 1.9 million people living with bladder cancer around the world, continence is not a side issue. It is central to what life with this disease actually feels like.




We are calling for three things.

1. First, continence needs to be part of the conversation at every stage of bladder cancer care, from the first appointment after diagnosis, through treatment and surveillance, all the way through recovery and beyond. It cannot wait until the problem becomes a crisis.

2. Second, preparation before major surgery must include continence as a core part of prehabilitation programmes, supported by nurses who are properly trained and resourced to deliver this in every setting, not only the most specialised ones.

3. Third, patients must receive honest, clear information about what their treatment will mean for their body, early enough to genuinely shape their choices.

Surviving bladder cancer is the beginning. Living well afterwards, with dignity, confidence and support, is what we should all be working towards. This World Continence Week, we are asking everyone connected to bladder cancer care to say that out loud.

## Our story

The World Bladder Cancer Patient Coalition was established in January 2019 by patient advocates from three national bladder cancer organisations who saw the need for a global bladder cancer coalition. Today, our Coalition unites 17 member organisations across 14 countries, sharing one vision: the best possible outcomes for people affected by bladder cancer, wherever they live. For the first time, people affected by bladder cancer have a force connecting patients, groups and organisations worldwide.

## Our network

The World Bladder Cancer Patient Coalition is a global community of bladder cancer patient organisations dedicated to improving the lives of people affected by bladder cancer. Our strength comes from our members, affiliates and partners. Together, we run joint initiatives, collaborate on advocacy and awareness-raising, and share tools, information and resources. If you would like to become a member or start a bladder cancer patient group in your country, visit our website to learn more and get in touch with us directly.

Our Scientific Advisory Board (SAB) is an independent advisory body of world-leading professionals in urology, oncology, radiotherapy, pathology, nursing and research. They guide our work on scientific and clinical matters, ensuring that all our resources and patient information are accurate and trustworthy.

## You can find us here:

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