World Bladder Cancer Patient COALITION

The first chance is the best chance:

An opinion piece on bladder cancer, surgical quality and life after treatment



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WBCPC Opinion Pieces 2026

The first chance is the best chance:

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Every year, **635,264 people** around the world are told they have bladder cancer. That is more than one person every minute, each with a family, a job and a life that the diagnosis suddenly puts on hold. Around **2 million** people are living with bladder cancer today, making it the eighth most common cancer worldwide.

In September 2026, patients, survivors, carers and patient organisations from across the world met in Hong Kong for the Public Day of the World Bladder Cancer Patient Forum 2026. Two members of the World Bladder Cancer Patient Coalition (WBCPC) Scientific Advisory Board shared the latest research with the community. **Prof. Jeremy Teoh**, Professor and Assistant Dean (External Affairs) at the Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong, spoke about non-muscle-invasive bladder cancer (NMIBC). **Dr Makarand Khochikar**, Patron Director and Head of the Department of Urology and Urologic Oncology at KIMS UAIMS Hospital, Sangli, and Chief Uro-oncologist at Siddhi Vinayak Ganapati Cancer Hospital, Miraj, India, spoke about muscle-invasive bladder cancer (MIBC).

The questions in the room were the ones people affected by bladder cancer ask everywhere. ***Will my cancer come back? Do I have to lose my bladder? Can I afford this? Will I get my life back?*** This opinion piece draws on both talks, on the questions patients put to the speakers, and on what we collectively believe now needs to change.

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38%
Of patients face a chance of the cancer coming back within a year, yet only around a 1% chance of it progressing in the same period

"Intrinsically, it may not be a bad cancer"

Around three in four people diagnosed with bladder cancer have NMIBC, where the cancer sits in the inner lining of the bladder and has not grown into the muscle wall. For many, it becomes a long relationship with the disease: repeated check-ups, repeated procedures and the worry that comes before each one.

Prof. Teoh began with a question he puts to his trainees: is bladder cancer a "good" cancer or a "bad" one? Widely used risk tables show the paradox. A patient can face a **38% chance of the cancer coming back within a year**, yet only around a **1% chance of it progressing in the same period.** More than one in three people may need further treatment within twelve months, even though very few will see their cancer become more serious.

"Is bladder cancer a "good" cancer or a "bad" one? Widely used risk tables show the paradox."

"Why are we seeing such a high recurrence rate but a low progression rate? Is it really the tumour biology, or is there something wrong in the way that we're managing the disease?"

He described five ways the cancer can return, from small tumours missed during the first look inside the bladder (cystoscopy) to cancer cells released during surgery that settle and grow again. Smoking and exposure to other harmful chemicals can also affect the whole bladder lining, so new tumours appear over time.

> *"That's the first opportunity and the best opportunity to get it well done."*

Much of the answer lies in the very first operation, known as Transurethral Resection of Bladder Tumour (TURBT). Standard TURBT removes the tumour in pieces, and the quality varies. When surgeons go back a few weeks later, a systematic review found cancer still present in **17 to 67%** of people with early-stage (Ta) tumours and **20 to 71%** of those with T1 tumours. *"That's the first opportunity and the best opportunity to get it well done,"* Prof. Teoh said.

His own research offers one answer. En bloc resection removes the tumour in a single piece, which keeps cancer cells from scattering and lets pathologists check that the edges are clear. In a trial across 13 hospitals in Hong Kong with **350 patients**, it lowered the chance of the cancer returning within a year from **38.1% to 28.5%**, with no increase in complications. That is roughly one fewer recurrence, and one fewer round of treatment, for every ten people treated, and every urology trainee in Hong Kong now learns the technique.

Newer treatments are also emerging for people whose cancer keeps returning after Bacillus Calmette-Guérin (BCG), a treatment that uses the immune system inside the bladder. Access varies widely, and some are not yet available in Asia.

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Follow-up is a burden of its own. People with high-risk disease have a camera test every three months for two years, every six months for the next three, and then once a year for life. As a member of the *European Association of Urology (EAU) guidelines panel on NMIBC*, Prof. Teoh helped review more than 1,700 papers on urine tests that could one day replace some of these checks, and found only three randomised trials. He called on industry to close that gap: *"It's not just about making money or selling something. It's about creating the evidence needed to drive impact."*

When a patient in the room shared her fear that, after two recurrences and three years of BCG, she might never truly be free of cancer, Prof. Teoh was reassuring. Most recurrences happen early, he explained, and after the first year the risk tends to level off. *"I encourage you to be more optimistic."* Dr Khochikar added his own reminder: I like to say that BCG, he said, stands for *"bladder cancer gone"*. It was a light-hearted word of encouragement to the patient, not a medical promise: BCG lowers the chance of the cancer coming back, but it cannot guarantee that it will not.





"If the disease is gone completely, why are we removing the bladder?"

For people with MIBC, where the cancer has grown into the muscle wall of the bladder, the standard treatment has long been surgery to remove the bladder (radical cystectomy). In men this usually includes the prostate, and in women it often includes the womb (uterus) as well as other sexual reproductive organs in surrounding area. Urine then leaves the body either through a new bladder made from a piece of bowel (neobladder) or through an opening on the abdomen (stoma) into a bag.

Dr Khochikar has seen this change over 30 years of practice. Chemotherapy before surgery (neoadjuvant chemotherapy) is now standard, shrinking the tumour and adding an estimated **5 to 7%** to survival. Trials such as NIAGARA have since shown that adding immunotherapy brings a further survival benefit, and newer combinations offer options for people whose kidneys cannot cope with standard chemotherapy

For some people, these treatments work so well that scans show no visible cancer before surgery and the pathologist finds none in the bladder afterwards. Patients notice. *"The patients keep on asking, if the disease is gone completely, why are we removing the bladder?"* Dr Khochikar said. Blood tests that look for tiny traces of tumour DNA (liquid biopsy, or ctDNA) may one day show who can safely keep their bladder, and he expects this to be a major focus of research over the next five to six years.

For a surgeon who travelled the world to learn how to remove bladders, it is a striking moment. *"At the end of 30 years, I'm questioning myself: have I done the right things? Should I be removing bladders in future, or training people to remove them? Life has come full circle."*

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A survivor living with a stoma asked whether the other organs removed with the bladder could be spared, a question that matters greatly to women, who make up one in four people with bladder cancer. In men, Dr Khochikar explained, keeping the prostate risks leaving a second cancer behind, as one is found unexpectedly in **10 to 15%** of removed prostates in some centres and up to **30%** in others. In women, the uterus can sometimes be preserved, though this is technically demanding and carries risks, and he has cared for a small number of young women who went on to have children after surgery.

"We have seen wonders in removing disease, but at what cost?"

Progress in bladder cancer has a price, and patients and families are often the first to pay it. Dr Khochikar pointed to a forthcoming article in The Journal of Urology on the rising cost of bladder cancer care. In 2003, a radical cystectomy, then the mainstay of treatment, cost around **US$ 45,000**. Adding today's drug therapies can push the cost of treating a single person into the hundreds of thousands of dollars, before counting the cost of managing side effects such as skin reactions.

In India, where he practises, many people have no insurance. *"People have to sell their houses, all their savings, to get the treatment for cancer,"* he said, and the same is true wherever public systems cannot cover the cost. The expense does not stop when treatment ends. A person with a urostomy (a stoma that carries urine into an external pouch) may spend **US$ 20 to 30 every week, for the rest of their life**, on bags and the adhesive flanges that hold them in place.



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Prof. Teoh raised the same concern about newer treatments for NMIBC, which must be weighed against their side effects and the extra hospital visits they require. Dr Khochikar was clear that cost must never become a reason to offer people a lesser standard of care. But innovation that people cannot afford, or cannot reach, does not close the care gap.

"The patients teach you quite a lot"

The part of the session many in the room will remember was Dr Khochikar's account of what three decades of patients have taught him. For the people he treats, losing the bladder is about far more than an organ. ***"It's not losing an organ, but what kind of life they're going to live."*** In a country as diverse as India, that life is shaped by faith, work, climate, clothing and money, and good surgery has to fit all of it.

Some lessons changed his technique. Patients asked whether their flanges could last longer, so he began making the stoma spout slightly longer. In a hot climate, where adhesives break down quickly, the change helped flanges last around 15 days instead of about a week, roughly halving the cost of supplies. For a keen golfer, he placed the stoma on the left so it would not get in the way of his swing.

Other solutions came from patients themselves. One man cut a discreet slit in his trousers so he could empty his bag quickly in a public toilet. Another, determined to keep swimming, made a padded cover from his son's old school bag. Others wanted to keep praying at the mosque or the temple without worrying about leaks or a visible stoma. ***"I won't take a personal credit," Dr Khochikar said. "It's the patients who have done that."***

One story has stayed with him. A woman who sold vegetables from an open stall, wearing a sari that left her abdomen visible, came back two weeks after a successful operation. ***"You cured me, but you killed me as well,"*** she told him, because customers had stopped coming near her stall. That evening, his wife, a gynaecologist, sewed her a pouch from sari fabric to cover the stoma, with room for money and a phone. The woman went back to work, and Dr Khochikar now runs a foundation that helps patients develop and share ideas like these.

Seen this way, life after treatment is not a footnote to care. It is the measure of whether care has worked. "You are guiding and teaching us a lot," Dr Khochikar told the patients and advocates in the room. "Keep motivating us."

"Patients do deserve a lot more discussion"

A patient advocate from Australia asked what patient organisations can do when new techniques and treatments are not reaching patients.

Dr Khochikar's answer began with the first appointment. "***The first chance is the best chance of curing bladder cancer,"*** he said. ***"Your battle of bladder cancer is won or lost in your first assessment."*** He urged patient organisations to turn international guidelines into simple checklists people can bring to appointments. If you have blood in your urine, the most common warning sign of bladder cancer, have you had an ultrasound scan? Has your urine been tested for cancer cells? Have you had the other tests the guidelines recommend?

He also cautioned against overload. Many patients now arrive with stacks of printouts and chatbot answers, and the line between too little and too much information is a fine one. A patient advocate from South Africa added that what matters is not only what people are told, but when.

A doctor may see someone for 15 to 30 minutes every few weeks, and without a planned approach to information along the way, people will look for answers elsewhere.

Dr Khochikar's own answer is peer support. For 30 years, he has kept in touch with former patients who are willing to talk to people facing the same decisions, and more than 700 patients and survivors are now part of this network. Anyone considering bladder removal is invited, with consent on both sides, to speak to someone who has been through it. ***"The patients are the best counsellors,"*** he said. ***"The survivors."***

Prof. Teoh offered a partnership. With the evidence for en bloc resection now in, he wants patients to understand their surgical options before that first operation, and offered to work with patient organisations on webinars, websites and other ways of sharing knowledge. "I think patients do deserve a lot more discussion on that."

Stoma



A surgically created opening that allows urine or waste to leave the body and be collected in a bag. It may be used after bladder removal.

Our call to action

As Chief Executive Officer of the World Bladder Cancer Patient Coalition, I listened in Hong Kong as patients from every continent asked the same questions: will my cancer come back, will I keep my bladder, can I afford this, and will I get my life back? The science is moving fast, but progress only counts when it reaches the people who need it most – a person sitting in front of their doctor facing a bladder cancer diagnosis.

When bladder cancer is found early, up to **90% of people survive for 5 years or more**, which is why anyone who notices blood in their urine should see a doctor without delay. We know more than ever about treating bladder cancer well. The task now is to make sure that knowledge reaches every person, in every country, from their very first appointment.

We are calling for three things:

1. First, every person with suspected bladder cancer deserves a high-quality first assessment and first operation where appropriate, carried out to international guideline standards. Training, audit and investment in surgical quality, including techniques such as en bloc resection, should be priorities for health systems, because the first chance is the best chance.

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What to look out for

- Pain when urinating
- Lower abdominal/ pelvic pain
- Blood in urine
- Frequent urination / urgency

2. Second, new treatments must come with a plan for access and affordability. Regulators, Health Technology Assessment (HTA) bodies, health systems and industry must work with patient organisations so that innovation reaches people where they live without obstacles of socioeconomic status and income, and so that the lifelong costs of living with a stoma are recognised and supported.

"Will I keep my bladder, can I afford this, and will I get my life back?"

3. Third, quality of life must be treated as an outcome of care, not an afterthought. Shared decision-making, well-timed information and peer support should be part of every care pathway, and research into bladder-sparing and organ-sparing treatment should be shaped by what patients say matters most to them.

Surviving bladder cancer is the goal. Living well afterwards, at work, at prayer, at home and in the community, is how we will know we have reached it.

Want to understand your options better? Read about bladder cancer, its stages and treatments and explore the work of our Scientific Advisory Board. You can also download our free, plain-language factsheets on symptoms, diagnosis, treatment and more, available in several languages. If your organisation would like to work with us on patient information, get in touch with us.



You can also watch the full session recording, featuring Prof. Teoh and Dr Khochikar's talks and the discussion with patients at the World Bladder Cancer Patient Forum 2026 Public Day.

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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The World Bladder Cancer Patient Forum 2026 is made possible with the support of our Global Impact Partners, Johnson & Johnson and ImmunityBio, Premier Partners Astellas, AstraZeneca and Ferring, and our Sponsors Roche and MSD. The content of the event remains the sole responsibility of the World Bladder Cancer Patient Coalition.