

Shared Decision Making – bladder cancer

Next clinical review date March 2018

Deciding what to do about bladder cancer

This short decision aid is for people with bladder cancer, to help them decide what treatment to choose after having had an operation (telescopic surgery) to take out cancer from the bladder. It is for people with cancer that is likely to spread (aggressive) but has not spread into the main muscle coat of the bladder. This is called high-risk non-muscle-invasive bladder cancer.

The options are:

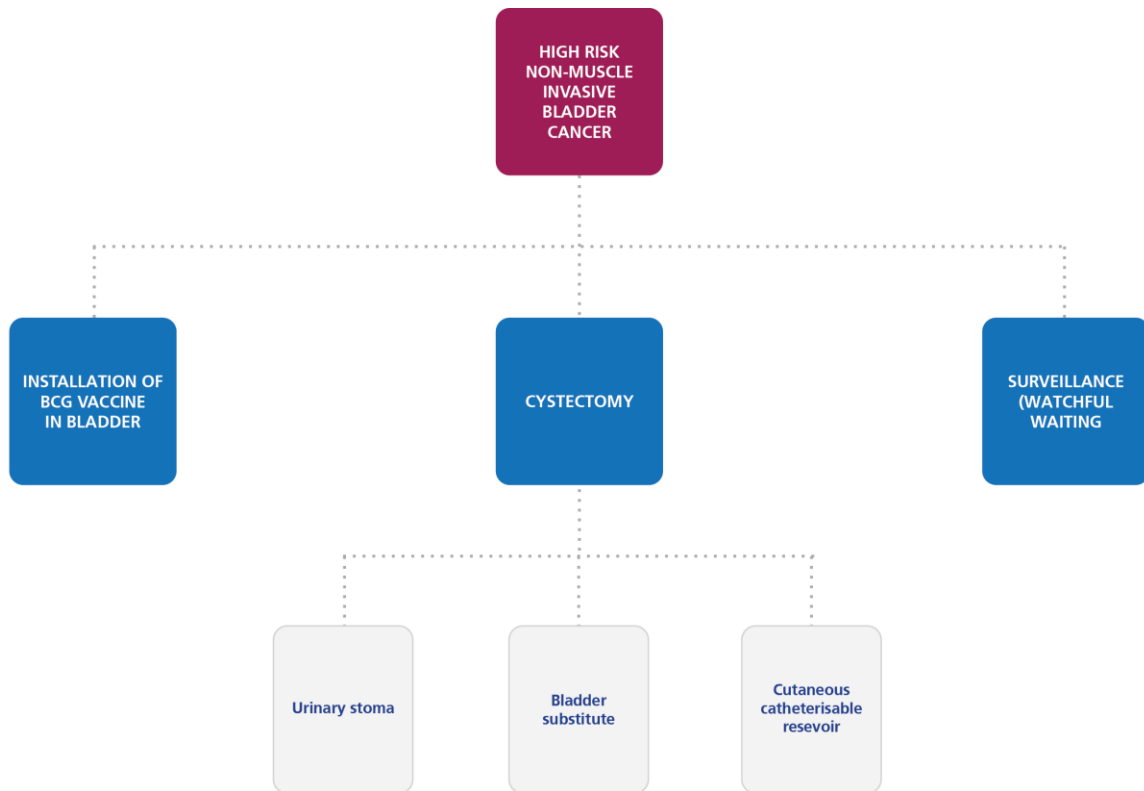
Two common cancer treatments, radiotherapy and chemotherapy, do not work well against high-risk non- muscle-invasive bladder cancer. So, after telescopic surgery to remove the cancer from the bladder, the main options are:

Putting the Bacillus Calmette-Guérin (BCG) vaccine into the bladder

Surgery to remove the bladder completely (called cystectomy)

Watchful waiting, where a specialist (urologist) does regular monitoring with telescopic bladder checks

(cystoscopy), to see whether the cancer has come back in the bladder.



What are my options?

	BCG Vaccine	Surgery to remove bladder (Cystectomy)	Watchful Waiting
What is the treatment?	Putting the Bacillus Calmette-Guérin (BCG) vaccine into the bladder	Surgery to remove the bladder completely (called cystectomy).	Where a specialist (urologist) does regular monitoring with telescopic bladder checks (cystoscopy), to see whether the cancer has come back in the bladder.
What is the effect of the treatment on length of life?	<p>Some studies show that between 60 in 100 and 70 in 100 people having BCG vaccine treatment will live for at least another five years.[7] [8] Doctors use five-year figures to measure how well people do after cancer treatment. That doesn't mean people won't live longer than five years.</p> <p>Up to half of these people will have had surgery to remove their bladder (cystectomy) because their cancer came back or worsened after their BCG treatment. Not everyone whose cancer comes back after BCG can be cured. That's why the numbers of people living at least five years is slightly lower for people who choose to have BCG as their first treatment, compared to those who choose to have surgery straight away. Results vary a lot by what type of cancer people have, what stage it is, and other individual circumstances. It is important that people know their individual chance of cure. A urologist can explain</p>	<p>Some studies show that between 75 in 100 and 85 in 100 people who have surgery to remove their bladder (cystectomy) will live for at least another five years.[7] [9] Doctors use five-year figures to measure how well people do after cancer treatment. That doesn't mean people won't live longer than five years.</p> <p>Surgery to remove the bladder does not always mean living longer. Results vary a lot by what type of cancer people have, what stage it is, and other individual circumstances. It is important that people know their individual chance of cure. A urologist can explain what the individual chance of cure is for cystectomy for each particular form of bladder cancer.</p>	<p>We don't know how long people live if they choose watchful waiting. There are no studies looking at this.</p> <p>Length of life for people having watchful waiting is likely to depend partly on whether the cancer returns or spreads. It is not usually possible to cure cancer that has spread. If a person's general health is poor, the risk to their life from other health conditions may be greater than the risk from the bladder cancer.</p> <p>Watchful waiting does not involve active treatment for bladder cancer, so it does not cure the cancer.</p>

	<p>what the individual chance of cure is for BCG treatment for each particular form of bladder cancer.</p>		
--	--	--	--

	BCG Vaccine	Surgery to remove bladder (Cystectomy)	Watchful Waiting
<p>What is the effect of the treatment on your daily life?</p>	<p>People who have BCG vaccine treatment need to make time for appointments. The BCG vaccine is usually given once a week for six weeks. If the treatment is working well it can then be given every six months, once a week for three weeks. Some people have treatment for up to three years. This is called maintenance treatment. [10] [11]</p> <p>People can go about their daily lives between treatment appointments. Treatment should not have much effect on the ability to work, exercise, or socialise. One group of people having BCG vaccine treatment felt that their quality of life did not change much during treatment.[12] [13]</p> <p>People having BCG treatment need to attend hospital for treatment with BCG and for regular telescopic checks of the bladder to make sure that the cancer has not come back.</p>	<p>People who have their bladder removed need to get used to another way of managing the drainage of urine from their body. The choices are a urinary stoma (a bag on the abdomen into which urine drains) or an internal pouch made from bowel, which replaces the bladder. This pouch is sometimes connected to the urethra to allow people to hold and pass urine more or less normally (bladder substitute). A bladder substitute may not be suitable for some people. Another option is to have the pouch connected to the inside of the abdominal wall and emptied through a plastic tube (catheter) several times each day (called a cutaneous catheterisable reservoir).</p> <p>People who have surgery to remove the bladder need regular hospital appointments to check that the cancer has not come back, and to check that urinary drainage is working well.</p> <p>It can take time to adjust to the way urine drainage works. Most people find having a stoma and using an</p>	<p>People who have watchful waiting need telescopic checks of the bladder to make sure that the cancer has not come back. We don't know how watchful waiting affects quality of life. Not knowing if the cancer will come back may cause considerable anxiety for some people. Watchful waiting should not affect the ability to work, exercise, or socialise. These activities need to be fitted around appointments.</p>

		<p>external bag simplest and easiest to use. Either of the internal pouches (bladder substitute or catheterisable reservoir) requires more time and effort to get used to how they work and to learn to use them effectively. People who have an internal pouch need more frequent follow-up visits after surgery. Some people find it hard to come to terms with the stoma, or to manage it. This could affect relationships with partners, family, friends, or work colleagues. After recovery from surgery, people are usually able to return to their usual work, unless they do heavy physical work.</p>	
--	--	---	--

	BCG Vaccine	Surgery to remove bladder (Cystectomy)	Watchful Waiting
<p>What is the effect on urinary continence?</p>	<p>BCG vaccine treatment is very unlikely to give you permanent urinary incontinence (leakage of urine). Most people find that they have to pass urine more frequently by day and night during and for a few weeks after each set of BCG treatments.</p>	<p>People who have had their bladder removed may have some urinary incontinence, depending on what type of surgery they have had.</p> <p>A stoma (external bag) can leak if the bag does not fit the skin correctly. Specialist stoma nurses may be able to sort out these problems.</p> <p>People who have a bladder substitute may find it difficult to control their urinary flow at first, but are not likely to think of themselves as incontinent. After this surgery, about 90 in 100 people say they can control their urination by day, and about 80 in 100 people say they can control their urination by night.[14] People who do have problems with urinary continence do not often think the problem is important enough to need further surgery.</p>	<p>Watchful waiting does not cause urinary incontinence. For people who have watchful waiting who have feelings of needing to urinate often, this is likely to stay the same or possibly get worse if the cancer comes back or spreads.</p>

	BCG Vaccine	Surgery to remove bladder (Cystectomy)	Watchful Waiting
<p>What is the safety of the treatment (risks and side effects)?</p>	<p>Fewer than 5 in 100 people with bladder cancer get serious side effects with BCG vaccine treatment.[15] [16] [7]</p> <p>Some common side effects that people get when they have BCG vaccine treatment include problems passing urine, pain when passing urine, feeling the need to pass urine more often than usual, urine infection, and blood in the urine. About 70 in 100 to 80 in 100 people who have BCG will have these symptoms for a few days or a few weeks, around the time of their BCG treatment. About 30 in 100 people get a fever (high temperature) with BCG vaccine treatment, which may last one or two days.</p> <p>Some people will get problems with their bladder, prostate, testicles, or kidneys, or other occasional effects elsewhere in the body, as a result of inflammation caused by the BCG.</p> <p>Most patients who are treated successfully with BCG vaccine do not complete the full course of maintenance treatments (up to three years). Each set of three treatments causes more bladder irritation, and so they choose to stop having further treatments before completing the full course.[15] [17]</p>	<p>Some people die from surgery to remove their bladder. International figures show this happens to between 1 in 100 and 4 in 100 people.[18] NHS hospitals carrying out this surgery have to show that their rates of people dying are no higher than 3.5 in 100. Most NHS hospitals would expect to have a risk of death of no more than 2 in 100.</p> <p>Between 25 in 100 and 50 in 100 people having surgery to remove their bladder have a major complication that will be treated successfully, but might need further surgery. They may need to stay longer in hospital. [18] These complications can include angina, a heart attack, abnormal heart rhythms, mini-strokes or a stroke, chest infection, or a blood clot in the leg or in the chest (deep vein thrombosis or pulmonary embolus), as well as infection or reopening of the abdominal wound, and leakage from the surgical joins (anastomoses) created in the bowel and between the kidney drainage pipes (ureters) and the urinary drainage system.</p> <p>You can ask the urologist what the risk of death and major complications following cystectomy is in your hospital.</p>	<p>There are no direct side effects from watchful waiting, other than the risk that the cancer may get worse.</p>

	BCG Vaccine	Surgery to remove bladder (Cystectomy)	Watchful Waiting
What is the effect of the treatment on your sex life?	Having BCG vaccine treatment does not seem to affect people's sex life.[12]	<p>Surgery to remove the bladder will usually have some effect on people's sex life, for both men and women.</p> <p>Almost all men will get erection problems after surgery to remove the bladder, because the nerves that control erection may be damaged during surgery. This means that almost all men having this surgery will either not get any erections, or will not get erections firm enough for sex. Men almost always have their prostate gland taken out during the operation. This will mean that they cannot ejaculate after surgery.</p> <p>In women, surgery to remove the bladder can make the vagina shorter and narrower. This may make having sex painful or difficult. The womb and ovaries may also have been taken out during surgery. This will mean they will not be able to have children.</p>	Watchful waiting does not seem to affect people's sex life.

What are the pros and cons of each option?

People with bladder cancer have different experiences about the health problem and views on treatment. Choosing the treatment option that is best for the patient means considering how the consequences of each treatment option will affect their life.

Here are some questions people may want to consider about treatment for bladder cancer:

- Do they want the treatment that gives them the best chance of curing their bladder cancer?
- Do they want the treatment that is least likely to affect their daily life?
- Are they willing to spend time in hospital, or recovering from treatment?
- Are they willing to take the risk of side effects or complications from treatment?
- How important is it that their sex life is not affected by treatment?

How do I get support to help me make a decision that is right for me?

People using this type of information say they understand the health problem and treatment choices more clearly, and why one treatment is better for them than another. They also say they can talk more confidently about their reasons for liking or not liking an option with health professionals, friends and family.

References

7. Shahin O, Thalmann GN, Rentsch C, et al. A retrospective analysis of 153 patients treated with or without intravesical bacillus Calmette-Guerin for primary stage T1 grade 3 bladder cancer: recurrence, progression and survival. *Journal of Urology*. 2003; 169: 96-100.
8. Griffiths TR, Charlton M, Neal DE, et al. Treatment of carcinoma in situ with intravesical bacillus Calmette-Guerin without maintenance. *Journal of Urology*. 2002; 167: 2408-2412.
9. Stein JP, Lieskovsky G, Cote R, et al. Radical cystectomy in the treatment of invasive bladder cancer: long-term results in 1,054 patients. *Journal of Clinical Oncology*. 2001; 19: 666-675.
10. MacMillan Cancer Support. BCG treatment. Available at <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bladder/Treatinglyearly/BCGtreatment.aspx> (accessed on 23 January 2013).
11. Lamm DL. Efficacy and safety of bacillus Calmette-Guerin immunotherapy in superficial bladder cancer. *Clinical infectious diseases: an official publication of the Infectious Diseases Society of America*. 2000; 31 (supplement 3): S86-S90.
12. Mack D, Frick J. *British Journal of Urology*. 1996; 78: 369-371.
13. Bohle A, Balck F, von Weitersheim J, et al. *Journal of Urology*. 1996; 155: 1221-1226.
14. Hautmann RE, Abol-Enein H, Davidson T, et al. ICUD-EAU international consultation on bladder cancer 2012: urinary diversion. *European Urology*. Available at [http://www.europeanurology.com/article/S0302-2838\(12\)01003-2/fulltext](http://www.europeanurology.com/article/S0302-2838(12)01003-2/fulltext) (accessed on 23 January 2013).
15. Gontero P, Bohle A, Malmstrom PU, et al. The role of bacillus Calmette-Guerin in the treatment of non-muscleinvasive bladder cancer. *European Urology*. 2010; 57: 410-429.
16. Shelley MD, Court JB, Kynaston H, et al. Intravesical bacillus Calmette-Guerin versus mitomycin C for Ta and T1 bladder cancer (Cochrane review). In: *The Cochrane Library*. Wiley, Chichester, UK.
17. van der Meijden AP, Sylvester RJ, Oosterlinck W, et al. Maintenance Bacillus Calmette-Guerin for Ta T1 bladder tumors is not associated with increase toxicity: results from a European Organisation for Research and Treatment of Cancer Genito-Urinary Group Phase III Trial. *European Urology*. 2003; 44: 429-434.