Endorsements

Every case and every patient is different. The information in this publication is of a general, non-specific nature. It is not intended, and should not be used as a substitute for the advice of qualified medical professionals.

While we have made every effort to ensure that the information in this publication is accurate, we cannot guarantee there are no errors or omissions. We cannot accept responsibility for any loss resulting from any act, or failure to act based on the information in this publication.

DISCLAIMER
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOREWORD</td>
<td>3</td>
</tr>
<tr>
<td>1. THE BLADDER</td>
<td>4</td>
</tr>
<tr>
<td>2. DIAGNOSIS</td>
<td>7</td>
</tr>
<tr>
<td>3. WHAT IS BLADDER CANCER?</td>
<td>9</td>
</tr>
<tr>
<td>4. TREATMENT OPTIONS</td>
<td>14</td>
</tr>
<tr>
<td>4.1 Cystoscopy &amp; TURBT</td>
<td>15</td>
</tr>
<tr>
<td>4.2 BCG (Bacillus Calmette-Guerin)</td>
<td>16</td>
</tr>
<tr>
<td>4.3 Intravesical Chemotherapy</td>
<td>16</td>
</tr>
<tr>
<td>4.4 Bladder Removal with Urinary Diversion (Cystectomy)</td>
<td>17</td>
</tr>
<tr>
<td>4.5 Urinary Diversion</td>
<td>18</td>
</tr>
<tr>
<td>a. Ileal Conduit</td>
<td>20</td>
</tr>
<tr>
<td>b. Continent Catheterisable Pouch</td>
<td>21</td>
</tr>
<tr>
<td>c. Neobladder</td>
<td>22</td>
</tr>
<tr>
<td>4.6 Systemic Chemotherapy</td>
<td>23</td>
</tr>
<tr>
<td>4.7 Radiation Therapy</td>
<td>24</td>
</tr>
<tr>
<td>4.8 Immunotherapy</td>
<td>25</td>
</tr>
<tr>
<td>5. RECOVERY AND REHABILITATION</td>
<td>26</td>
</tr>
<tr>
<td>6. LIFE AFTER TREATMENT</td>
<td>29</td>
</tr>
<tr>
<td>7. FOR FAMILIES &amp; FRIENDS</td>
<td>35</td>
</tr>
<tr>
<td>8. THE SUPPORT TEAM</td>
<td>39</td>
</tr>
<tr>
<td>9. STAGING TERMINOLOGY</td>
<td>42</td>
</tr>
<tr>
<td>10. GLOSSARY</td>
<td>46</td>
</tr>
<tr>
<td>11. ABOUT BCACF</td>
<td>48</td>
</tr>
</tbody>
</table>
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Technical Editor
Assoc. Prof. Nathan Lawrentschuk
PhD MBBS FRACS (Urology)

Content Development
Anthony Moore
Belinda Barro
Colin Bridges
Gioele Cardilli
Kath Schubach
Simon Moore

Edition 1 & 2 Designed by
Leap Marketing
Edition 3 re-designed by
Rita Ferreira (Gigante – Edição e Design)

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<tbody>
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<tr>
<td>11</td>
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</tbody>
</table>

Bladder Cancer Australia Charity Foundation (BCACF) was formed in 2015 to campaign for Awareness, Screening, Treatment and Research for Bladder Cancer.

BCACF is a fully registered Australian charity ACN: 59119773067, with full tax deductibility status for donations. The Foundation currently receives no government funding. You can assist our work by:

• Making a tax deductible donation
• Signing our online petition

Just visit our web site at:
www.bladdercancer.org.au

Thank You
FOREWORD

Bladder cancer is the fifth most common cancer in men, but is only half as common in women. While it can occur at any age, it is rare under the age of 50 years and usually presents in older people. As with many cancers, there is a strong, but not exclusive link to cigarette smoking.

The consequences of bladder cancer may be devastating, yet it represents a malignancy that is rarely talked about, or considered by most people. Consequently, there is a lack of community awareness, resources and research for this cancer.

**Bladder Cancer Australia Charity Foundation** was formed to help address those issues. Our objectives are to increase awareness of the disease in both the general and political communities, and to provide information resources for patients, doctors and health care professionals.

This booklet, and our web site – bladdercancer.org.au – are just the beginning. Over coming months we aim to provide further resources, but this will only be possible with community support, and that of the sponsors who made this publication possible.

Please join these organisations in support of our foundation.
1. THE BLADDER

The urinary bladder is a reservoir or sac in the pelvis – just above and behind the pubic bone of the pelvis. The pelvis is the bony structure which forms our hips. The bladder is almost the same in men and women.

1. Human urinary system

The bladder holds or stores urine until it is socially convenient to pass urine. We urinate out through a tube (the urethra). Muscles act like valves just below the bladder by encasing the tube and keep the bladder closed, until we feel the need to pass urine. When going to the toilet, we relax the valves or “sphincters”, and we urinate. This empties the bladder.

An empty bladder is about the size and shape of a pear. As it fills with urine it expands and holds between 400 to 600 mL in most people (men usually about 100ml more than women).

There are three openings in the bladder – two incoming from above for the ureters (tubes from the kidneys which make urine) and one outgoing from below – the urethra (tube carrying urine out of the body which empties from the penis or above the vaginal opening).
Urine is made in the kidneys, and travels down the ureters to the bladder. Urine exits the bladder into the urethra, which carries urine out of the body. The urethra is longer in men (20cm) than in women (5 cm), because it goes through the penis.

The bladder is lined with skin (urothelium) and layers of smooth muscle tissue that stretch as it fills with urine. To understand bladder cancer, it is important to understand the make-up of the walls of the bladder. The main muscle of the bladder is called the detrusor muscle.

2. Layers of the bladder wall

Blood flow to and from the bladder is from many arteries & veins. Some of these blood vessels are named: the vesical arteries, the obturator, uterine, gluteal and vaginal arteries. In women, a venous network drains blood from the bladder arteries into the internal iliac vein.

Men need to understand how the prostate and bladder are connected, and how bladder cancer treatment affects them both. Often bladder cancer and prostate cancer can appear together.
The prostate gland is normally the size of a walnut but can enlarge, for a variety of reasons.

The prostate is located between the bladder and the penis and sits next to the rectum. It produces fluid that nourishes and protects sperm. During ejaculation, the prostate pushes this fluid into the urethra (urine tube in penis) and it is ejaculated with the sperm as semen.

3. Female/Male urinary and genital system
2. DIAGNOSIS

The earliest warning sign that there might be a problem somewhere in the urinary system would be a slight change in the urine. A small drop of blood in urine is undetectable to the naked eye. A few drops can make a minor colour change, and even more drops can make urine sit “heavier” in the toilet bowl. Pink urine is not good, (unless you ate a huge serve of rhubarb!) and if visible blood is present in the urine a doctor should be consulted urgently.

Blood in urine is not necessarily a definite indication of the presence of bladder cancer. It might be from a sore or a cyst, it might be from the kidneys, it could be many simple things, other than Bladder cancer. If a GP sees any concerning results, he or she will recommend further urine & blood tests to find out what is going on.

After these test results come back, and if there are concerns that there are cancer cells present the patient will be referred to a specialist – a Urologist (Urinary System Specialist), an Oncologist (Cancer Specialist) or, in some cases, a Urological Oncologist (a urologist with specialized training in cancers and cancer surgery).

The specialist will recommend the next steps from there, which will most likely include more tests. Blood and urine tests, X-Ray, Ultrasound Studies and Scans may all be required during final diagnosis and treatment discussions.
Get to the Doctor if you notice any change in your urine!

A urine test is quick and easy.

Early detection is the key to being cured!
3. WHAT IS BLADDER CANCER?

Bladder cancer is caused by abnormal cells in the bladder, which grow and divide in an uncontrolled way.

There are different types of bladder cancer:

- **Urothelial carcinoma** (formally known as transitional cell carcinoma) is the most common form of bladder cancer (80-90%) and starts in the urothelial cells in the bladder wall’s innermost layer.
- **Squamous cell carcinoma** begins in the thin, flat cells that line the bladder.
- **Adenocarcinoma** is a rare form which starts in mucus-producing cells in the bladder.
- **Small cell carcinoma** is rarer still. Less than 1% of all bladder cancers.
- **Bladder cancer** can also present in a hollow in the bladder wall, called a diverticulum.
- Occasionally other cancers from adjacent organs may invade directly into the bladder (prostate or uterus) or metastatic deposits (secondaries) may end up in the bladder from cancers in distant organs (e.g. breast, prostate, bowel cancers).

If any type of bladder cancer is undiagnosed and untreated, it can also spread to other areas of the body.

Most bladder cancers start in the innermost lining of the bladder, which is called the urothelium or transitional epithelium. As the cancer grows into or through the other layers of the bladder wall, through the muscle and into the fat, it becomes more & more dangerous. Sometimes it grows in a bladder pocket or diverticulum, which advances the danger.

Over time, the cancer can grow outside the bladder and into other organs & structures. When bladder cancer spreads, it often goes first to lymph nodes, the bones, the lungs, or the liver.
Spread of bladder cancer

As mentioned before, understanding bladder cancer requires understanding of the wall of the bladder:

4. The bladder wall

5. Bladder pocket (Diverticulum)
Invasive and non-invasive bladder cancer

Bladder cancers are sometimes described by how far they have grown into the bladder wall.

Non-invasive cancers are still in the inner layer of cells (the transitional epithelium) but have not grown into the deeper layers.

Invasive cancers have grown into deeper layers of the bladder wall. These cancers are more likely to spread and are harder to treat.

6. Invasive bladder cancer

A bladder cancer can also be described as superficial or non-muscle invasive. These terms include both non-invasive tumors as well as any invasive tumors that have not grown into the main muscle layer of the bladder. It is important to recognize that invasion, be it into the layer just below the skin (lamina propria) or the muscle itself, is more dangerous than that just on the surface. That is why it is important to know the stage of the tumour and how far it has invaded. (All stages are described in Chapter 10).
Papillary vs flat cancer (carcinoma)

Bladder cancers are also divided into 2 subtypes, papillary and flat, based on how they grow. Papillary carcinomas grow in slender, finger-like projections from the inner surface of the bladder toward the middle.

Flat carcinomas don’t grow toward the middle of the bladder at all, but along the wall.

7. Papillary vs flat cancer

8. CT Scan showing a papillary carcinoma, growing up from the bladder wall
There are two more sub classifications of bladder cancer:

• **Carcinoma in-situ (CIS)**
  In many other cancers (e.g. breast and liver cancers), a CIS is a “pre-malignant” condition and can be cured. However, in bladder cancer this is not the case as it is a dangerous, high-grade cancer that is very prone to recur, and also ultimately invade. It is usually treated aggressively, and may respond to local treatments more readily than other types of bladder cancer.

• **Urothelial Carcinoma (Transitional Cell Carcinoma or TCC)**
  This is an extremely common type of cancer found in the bladder and the urinary tract – also known as transitional cell carcinoma or TCC. TCC can be present in the “skin” that lines the insides of the kidneys, ureters, bladder and urethra.

**Other Urinary Tract Cancers**

Other cancers can occur in the urinary tract lining – squamous cell carcinoma, adenocarcinoma, small cell carcinoma and neuroendocrine cancers. These will usually be treated in a similar way to urothelial cancer but may act differently and have variations in approach.

Other cancers may also spread to the bladder (metastasis). Prostate cancer in men, uterine, cervical & breast cancer in women, and bowel cancer & melanoma in either sex can spread to the bladder. This sometimes necessitates removal of the bladder. If any cancer has spread to multiple organs, a larger operation may be required, called a pelvic exenteration (removal of all pelvic organs).

Please see Chapter 9 for a detailed explanation of the medical terminology for the different stages of bladder cancer.
4. TREATMENT OPTIONS

After urine tests and blood tests, and maybe ultrasounds or scans, the patient’s medical team will have a view of the severity of the problem, and how best to treat it.
4.1 Cystoscopy & TURBT

In many cases the next step after diagnosis is to have a cystoscopy. This is done under general anaesthetic. A tube is passed up the urethra into the bladder.

A cystoscopy might be done just to get more information about the cancer, to take a sample of the tumour for pathology tests, or it may be done to remove the cancer from the bladder lining at the same time. This operation to remove the cancer is called Trans Urethral Removal of Bladder Tumour (TURBT).

Most people with bladder cancer have this TURBT procedure to remove the cancer from the bladder lining. If the doctor completely removes the cancer during the TURBT operation, further treatment may not be required.

After the TURBT procedure, the cancer specimen goes to the lab to find out how severe and aggressive the cancer is. This information tells the doctor what further treatment might be required.

In many instances a “second look” TURBT is done a few weeks later to ensure that:

- all of the tumour was removed the first time around.
- to make sure no new tumours have developed.
- the doctors really understand the depth of invasion of the tumour into the bladder wall so that appropriate treatment is taken.

If the TURBT procedure & pathology indicate a high risk bladder cancer, another TURBT may be performed within a month or two of the first procedure, to check how far the cancer has grown.

If the cancer is serious, and beyond treatment with TURBT, the next step might be to use drugs to kill the cancer cells.
4.2 BCG (Bacillus Calmette-Guerin)

This treatment for bladder cancer uses an immunotherapy drug called Bacillus Calmette-Guerin (BCG), which is similar to the bacteria that causes tuberculosis. BCG is placed directly into the bladder through a catheter (tube) passed up the urethra. This is called intravesical therapy. BCG attaches to the inside lining of the bladder and stimulates the immune system to attack and destroy the tumour.

BCG is administered once weekly for up to 6 weeks. Another 6-week course may be administered if the tumour persists. The medical team may want to repeat the course for a few years, to be sure the tumour is eradicated. In some instances, after an unsuccessful course of the BCG treatment more radical surgery may be necessary. Every case is different.

BCG is generally well tolerated but can cause flu-like symptoms, chills, mild fever, fatigue, a burning sensation in the bladder, and bleeding from the bladder.

Interferon is another type of immunotherapy that can be given as intravesical therapy. It is sometimes combined with BCG if using BCG alone does not help treat the cancer.

4.3 Intravesical Chemotherapy

Chemotherapy (chemo) is the use of drugs to treat cancer. Moderate risk bladder cancer patients often are recommended for a single course of chemotherapy given into the bladder (intravesically) after the TURBT operation.

The chemo drug is put directly into the bladder through a catheter (tube) passed up the urethra. This type of chemo is used only for very early stage bladder cancers. This is sometimes done at the time of the TURBT or shortly after.

This type of treatment may also be considered for patients who have had BCG in the past, or cannot tolerate BCG. Just like BCG it is given over approximately 6 weeks via a catheter. If the intravesical BCG &/or chemo treatments fail or the cancer recurs then more radical treatment may be required.
4.4 Bladder Removal with Urinary Diversion (Cystectomy)

If the cancer has progressed, and cannot be completely eradicated by TURBT, BCG or chemotherapy, the medical team will normally recommend surgery to remove the bladder or in some cases, part of the bladder. If bladder cancer spreads outside the bladder, it can be fatal. So complete removal of the bladder is often the best way to stop an advanced tumour.

This is called a Radical Cystectomy and it is the removal of the whole bladder and nearby tissues and organs. For men, the prostate, seminal vesicles, part of the vas deferens and the urethra also may be removed. For women, the uterus, fallopian tubes, ovaries, and part of the vagina may be removed. In addition, lymph nodes in the pelvis are removed for both men and women. This is usually done in an extensive way, meaning all of the lymph nodes in the pelvis and even some just outside the pelvis are taken. This gives a better chance of accurately knowing if the cancer has spread and also a better chance of survival. Typically more than 10-15 lymph nodes are removed, but in recovery the body can usually compensate for the loss of these lymph nodes so there should be no long-term consequences.
Sometimes, where the cancer is small, it is possible to treat bladder cancer by removing only that part of the bladder with cancer – this is called a partial cystectomy. Unfortunately, this is only possible in a very few cases, the main reason being that the size and/or multiple number of tumours means that putting the bladder back together would simply not be possible. The other main reason is we know that the toxins that have bathed the bladder causing a high grade cancer will likely cause other cancers in the bladder lining. Urologists refer to this as a “field change” because the whole lining of the bladder is potentially affected by cancer – a bit like weeds in a lawn, where you can only see the big ones but there are lots of small ones ready to pop up. When removing the whole bladder the risk of another tumour popping up and having to undergo even more extensive surgery is eliminated. Also, opening a bladder is risky as urothelial cancer cells can escape and “seed” to other locations. So removal of the whole bladder is often the safest option, but if the cancer is small, partial cystectomy may be possible.

4.5 Urinary Diversion

Of course, if the whole bladder is removed, doctors need to create a new way for urine to be collected from the kidneys and ureters, stored and then removed from the body. This is called a urinary diversion.

There are 3 mains options for urinary diversion. In each case doctors and medical experts will advise on which option, or options are applicable and available.

SEE THE PATIENT SURVEYS FROM NEOBLADDER AND ILEAL CONDUIT SURVIVORS ON OUR WEBSITE:
WWW.BLADDERCANCER.ORG.AU/STORIES
10 a. Ileal Conduit
An opening in the abdomen and a tube with an external bag to collect urine, sometimes called an urostomy.

10 b. Continent Catheterisable Pouch
Using some bowel tissue, a pouch is made inside the abdomen to collect urine. An opening in the abdomen allows the internal pouch to be emptied via a tube.

10 c. Continent urinary reservoir (Neobladder)
A “new” bladder is made using some bowel tissue and connected to the urethra, so urine can continue to pass normally.
a. Ileal Conduit

With this procedure, the tubes that carry urine from the kidneys (ureters) drain into the last segment of the small intestine (ileum). The end of the ileum is then brought out through an opening in the abdominal wall. This opening in the abdomen, called a stoma, is connected to an external bag that gathers the urine as it drains from the ileal conduit.

Advantages:
- It is a relatively simple surgery.
- It requires less surgical and recovery time.
- There is no need for occasional catheterisation.
- No bowel tissue is used to create a reservoir, so less disruption to the bowel.

Disadvantages:
- There is a change in body image and perhaps clothing/dressing.
- The hole, or stoma, in the abdomen needs regular care.
- There is an external bag to collect urine, which could leak or smell (fortunately this is very rare with the newer appliances and materials).
- Urine could reflux back up into the kidneys, causing infections.

What is a urinary catheter?

In urinary catheterisation a latex, polyurethane, or silicone tube known as a urinary catheter is inserted into a patient’s bladder via the urethra. Catheterisation allows the patient’s urine to drain freely from the bladder for collection.
b. Continent Catheterisable Pouch

With this procedure, also known as the Indiana Pouch or Kock Pouch, a pouch is made out of a portion of the intestine (large or small). The tubes that carry urine from the kidneys (ureters) are attached to drain into this pouch. The urine flows freely in a downward direction from the kidneys into the pouch. A short piece of small intestine is then brought out through a small opening in the abdominal wall (a stoma). The stoma is very small and can be covered with an adhesive bandage. A one-way valve is surgically created to keep the urine inside the pouch. Several times a day, usually every four to six hours, a small, thin catheter must be passed through the stoma and into the pouch to empty the urine. An adhesive bandage is worn over the stoma at all other times (when not actively emptying the pouch). Sterile catheters are easy to carry on outings and trips.

Advantages:

- Urine is kept inside the body, in the reservoir, until it is ready to be emptied.
- No external bag is necessary.
- There is no odor.
- The risk of urine leaking is minimal.
- The small stoma can be covered with an adhesive bandage.
- The risk of a back up of urine into the kidneys is reduced.

Disadvantages:

- The surgical time is longer compared with the Ileal Conduit (additional 1-3 hours).
- Because bowel tissue is taken, the bowel is disrupted.
- Longer recovery time.
- There is the need to empty the pouch every four to six hours through the stoma using a tube or catheter.
- Between emptying, the valve should keep the patient dry but a small percentage will leak when the pouch is full.
c. Neobladder

With this procedure, a section of the small intestine is taken and stitched into a reservoir or pouch, which is connected to the urethra, so the patient can urinate through the penis or vaginal opening. The tubes that carry urine from the kidneys (ureters) are attached to drain into this “new bladder”. Urine is able to pass from the kidney, to the ureters, to the Neobladder, and through the urethra in a manner similar to the normal passing of urine. To be a candidate for this surgical procedure patients should be fit and healthy, and it is important to note that although termed a “new bladder”, medically it is, in fact, “a continent orthotopic urinary diversion”. This means that whilst the reservoir for urine storage sits in the same place as a normal bladder, it will never be exactly the same, no matter how hard doctors try to replicate the normal bladder. However, it can be trained to function very well in most people.

Advantages:

• The process of urination most closely matches normal urination.
• No hole in the abdomen (stoma) is needed.
• The kidneys are protected from urine back up and infection.

Disadvantages:

• Surgery time is somewhat longer.
• Recovery time is long and physiotherapy is required to get control of the Neobladder.
• Urinary Incontinence (leakage of urine) is normal after surgery while regaining control of urination, and may last up to six months.
• Some patients never get totally dry and always leak a few drips, requiring a pad in their underwear.
• Most patients need to get up 2-3 times at night to empty the Neobladder. Night time leaking is a big issue for some patients.
• Despite the surgery, some patients might not be able to empty the Neobladder well and will need to perform occasional catheterisation (passing tubing through the urethra into the pouch every four to six hours) for a prolonged period of time after surgery.
• Because bowel tissue is taken, the bowel is disrupted.
4.6 Systemic Chemotherapy

In systemic chemotherapy, the drugs are typically injected into the bloodstream through a vein (Intravenous / IV). The drugs then travel throughout the body. It is important to note that systemic chemotherapy is usually only given to higher risk bladder cancer patients, where the likelihood that the cancer will move to other parts of the body is high.

Systemic chemo can affect cancer cells far away from the main tumor (e.g. in lymph nodes, the liver, lungs). There are several basic types of systemic chemotherapy that can be used in various stages of treatment for bladder cancer:

- **Neoadjuvant chemotherapy** – this is given before surgery. The term adjuvant means as an “adjunct” or “addition to” the surgical treatment (cystectomy). The term neo literally means “new” or “first” treatment option.

- **Adjuvant chemotherapy** – this treatment option is given after the surgery (cystectomy) as an adjunct or addition. The decision to give this treatment will again be based on the final histopathology of the surgery and also how physically capable a patient is to receive the therapy. Also, the risk and benefits will be weighed up by your medical oncologist with you.

- **Salvage Setting Chemotherapy** – this can be given long after a surgical treatment in combination with radiation (see below) as a curative therapy, where delayed or late recurrence has occurred.

- **Palliative chemotherapy** – to help with symptom control where the cancer has spread, and metastatic disease exists. This form of treatment is unlikely to cure the cancer.

Unfortunately not everyone will respond to chemotherapy. The response rates will depend on the tumour type, grade and stage. There is continual progress in the search for better chemotherapeutic drugs, and patients’ medical teams will discuss and recommend available options.
4.7 Radiation Therapy

Radiation therapy is usually not used by itself as a primary curative treatment for bladder cancer, but it may be given in combination with chemotherapy as a treatment option. The combination of radiation therapy and chemotherapy may be used:

- To destroy any cancer cells that may remain after TURBT to avoid removing all or part of the bladder. This is known as a “bladder preservation strategy”. This may be appropriate, but only in a small number of patients.
- To treat a recurrence in the pelvis if it is not amenable to surgery.
- To relieve symptoms caused by a tumor, such as pain, bleeding, or blockage.
- To treat a metastasis (spread of the cancer to other organs or parts of the body) located in one area, such as the brain or bone.

Side effects from radiation therapy may include fatigue, mild skin reactions, and loose bowel movements. For bladder cancer, side effects most commonly occur in the pelvic or abdominal area and may include bladder irritation with the need to pass urine frequently during the treatment period.

Some people who cannot receive chemotherapy might receive radiation therapy to the bladder alone. Also, radiation may be given alone to palliate symptoms from the bladder such as recurrent bleeding.

Overall, radiation has an important role in treating patients with bladder cancer and urologists work closely with radiation oncologists as part of a multi-disciplinary team.

CONFUSED?
CHECK OUT THE GLOSSARY OF BLADDER CANCER TERMS AND CLASSIFICATIONS STARTING ON PAGE 42.
As discussed, BCG is a form of immunotherapy – that is stimulating the body's immune system to kill cancer cells. The BCG is given into the bladder (intravesically) and thus is only active at that location. However, in more advanced cases where metastatic disease is present clinicians are now exploring the use of Systemic Immunotherapy.

Immunotherapy, is the latest hope for curing bladder cancer. It is also called biologic therapy, and is designed to boost the body's natural defences to fight the cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. This is a new area of medicine, and many trials are opening up with these new agents.
5. RECOVERY AND REHABILITATION

If bladder cancer can be cured by a combination of chemotherapy, BCG treatment, TURBT & Immunotherapy, without any invasive surgery, patients often return to their old selves, with normal bladder, bowel, digestion and sexual function, in a matter of months. Of course, every patient is different, and some people have unpleasant side effects and reactions arising from the above treatments; but it appears that for most people, if a cure is achieved by these methods, recovery can be complete.

During and after many bladder procedures, doctors leave a tube in your urethra, connected to a plastic urine collection bag, for a short period of time. The tube is called a catheter and allows your urine to drain freely from the bladder while you are recovering.

Cystoscopy and TURBT

After Cystoscopy or TURBT, the catheter is usually taken out before you go home. Taking a catheter out is a little bit uncomfortable, but it slips out in a second and the feeling of relief is great!

Recovery Facts:

• It might hurt to urinate for a few hours or a few days. URAL, available from the chemist, may help relieve this discomfort.

• You might see blood, blood clots or foreign matter in your urine for a few days. This is normal and nothing to worry about. It’s just your bladder and tubes healing.

• A man’s penis might be sore for a few days. So might a woman’s genital and urethral area.

• Drink plenty of water. This flushes your urinary system and helps recovery on all levels. It also reduces your risk of getting a urine infection.

• Don’t drink alcohol for at least two weeks after your procedure.

• If you have been prescribed antibiotics, make sure you complete the full course so any nasty bacteria won’t get a chance to grow again.
• Eat a healthy, well-balanced diet. Your bladder will need to repair itself after surgery, so eating nutritious foods helps – proteins, fruits, vegetables. You should also eat high-fibre foods to help prevent constipation. If you’re constipated, it might put pressure on your bladder and cause unnecessary bleeding.

• Don’t do any heavy lifting, strenuous exercise or driving in the first two weeks after your surgery. But get out and walk... slowly at first.

• If you smoke, now is a great time to stop.

• If you find that you need pain relief, standard across the counter from a pharmacist/chemist painkillers such as paracetamol or anti-inflammatory medications (e.g ibuprofen) should help.

• Sexual activity can resume when you feel up to it. It’s normal to be uninterested for a while after these procedures.

• With most men, there is no change to erections after these procedures.

• Don’t rush it! Take some time off to recover. After Cystoscopy, put your feet up for a week. After TURBT, take a couple of weeks. Your body and mind will thank you for it.

**Cystectomy and Radical Cystectomy**

Surgical removal of the bladder and other organs is a big deal. It is major surgery that requires extended healing time, and it comes with a complete re-adjustment in many personal and intimate areas of life.

These are big adjustments, both physical and mental, that need to be acknowledged and addressed daily.

Lifestyle factors are also a critical part of the recovery and rehabilitation process:

• Healthy diet.

• Rest (night time and nap time).

• A staged exercise plan.

• Sunshine and fresh air.
**For Ileal Conduit patients** there is a long period of adjustment to an external bag & stoma maintenance.

**For Pouch patients** adjustment to a new method of urine disposal takes time and effort.

**Neobladder patients** will have a long course of pelvic floor physiotherapy, to strengthen the sphincter to enhance urine retention without leaking.

For all, there are changes, new habits to form, new cleanliness routines, new positive attitudes to form... More life to live!

The long term side effects of bladder cancer surgery depend on the procedure. Patients should talk with their doctor in detail to understand exactly what side effects or changes may occur and how they can be managed.

**Post-surgical side effects may include:**

- Delayed healing of wounds.
- Infections.
- Urinary discomfort after surgery.
- Blood in urine for a period after surgery.
- Stoma and genital skin irritations.
- Urine mucous (if a Neobladder may require catheterisation).
- For a Neobladder – urine leakage and incontinence; odour.
- Changes to bowel function including long term diarrhea.
- Long-term changes to diet.
- Sexual dysfunction in men and women due to nerve damage in the pelvis. In particular an inability for men to have natural erections, called Erectile Dysfunction (ED), after cystectomy.
- Psychological challenges for life changes.
6. LIFE AFTER TREATMENT

Associates of the BCACF have been collecting surveys on patient cystectomy outcomes for some years.

You can see full survey results on our web site: www.bladdercancer.org.au

From International Ileal Conduit Survey
34 male & 30 female respondents, 1 year + post surgery

<table>
<thead>
<tr>
<th>Have you had any changes in your bowel function since surgery?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Answer Options</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

From International Neobladder Survey
114 male & 40 female respondents, 1 year + post surgery

In surgery, you lost some bowel tissue, which was used to create your Neobladder. Have you had any changes in your bowel function since surgery?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response %</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>59.7</td>
<td>92</td>
</tr>
<tr>
<td>No</td>
<td>40.3</td>
<td>62</td>
</tr>
</tbody>
</table>
From International Ileal Conduit Survey
88 male & 81 female respondents, 1 year + post surgery

Regarding your return to your regular life after surgery, please tick all that apply

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response %</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had to completely change my wardrobe and dressing to accommodate the stoma and bag</td>
<td>22.7</td>
<td>15</td>
</tr>
<tr>
<td>2. I had very little difficulty making the transition to a stoma and bag</td>
<td>63.6</td>
<td>42</td>
</tr>
<tr>
<td>3. I became less confident about going out after my surgery</td>
<td>28.8</td>
<td>19</td>
</tr>
<tr>
<td>4. I do everything I did before surgery</td>
<td>56.1</td>
<td>37</td>
</tr>
<tr>
<td>5. I had a lot of difficulty getting to a completely dry, reliable stoma</td>
<td>9.1</td>
<td>6</td>
</tr>
<tr>
<td>6. I have no trouble with my new urinary diversion most of the time.</td>
<td>75.8</td>
<td>50</td>
</tr>
<tr>
<td>7. I have trouble with my new urinary diversion most of the time.</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

![Bar chart showing response percentages for each answer option]
Sexual Function Post Cystectomy

Sex is a huge part of being human, so to remove it from life, especially for active loving couples, is tough. But people going into this type of surgery need to have some hard facts.

**Men**
In men, the prostate, the seminal vesicles, and part of the vas deferens are also removed as part of the cystectomy surgery. This results in:

- Inability to ejaculate semen – permanent.
- Inability to have an erection after surgery – perhaps permanently.
- Mental challenges to masculinity.
- Re assessment of the “sexual future”.

Sexual function is going to change. Maybe erections will come back, maybe not, either way there are some upsides on sexual function after cystectomy:

- It is still possible to have a loving active sex life without a rampant male in the bedroom.
- It is possible for men to have an orgasm without an erection or an ejaculation.
- Penile Rehab can be fun – get adventurous.
- Sometimes, months or years later, erections can return.
- Sex drive naturally wanes over time.
- Life continues, with the ability to love family and friends and be loved in return.

Due to the extensive understanding of sexual dysfunction with prostate cancer treatments, the resources and allied health specialists available have increased dramatically. Counselling, use of adult toys and being confident about raising such issues is no longer taboo. Expect them to be discussed. If not, ask who would be the best person for you to meet or for resources to read.
From International Neobladder Survey
121 males, 1 year + post surgery

Since your Radical Cystectomy and Neobladder surgery, have you been able to attain any level of natural erection?

![Erection Levels Pie Chart]

- Strong Erection: 14%
- Fair Erection: 4%
- Some Swelling: 22%
- No Erection: 60%

From International Ileal Conduit Survey
119 male respondents

Which prescription medications work best for you to gain an erection?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response %</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Viagra</td>
<td>12.6</td>
<td>15</td>
</tr>
<tr>
<td>2. Cialis</td>
<td>11.8</td>
<td>14</td>
</tr>
<tr>
<td>3. Penile Injections</td>
<td>16.0</td>
<td>19</td>
</tr>
<tr>
<td>4. Vacuum Pumps</td>
<td>16.0</td>
<td>19</td>
</tr>
<tr>
<td>5. I don’t use any of the above</td>
<td>37.8</td>
<td>45</td>
</tr>
<tr>
<td>6. Other</td>
<td>5.8</td>
<td>7</td>
</tr>
</tbody>
</table>
Women
If nerve damage is minimal, it is possible to return to full sexual activity after bladder removal surgery. However, in females, sexual dysfunction may also occur. This is often because the majority of the vagina must be removed as it is closely related to the bladder and urethra. Also a cystectomy often involves accompanying removal of the uterus and ovaries (particularly in postmenopausal women). The vagina, although shortened, may stretch over time - there are exercises and techniques to assist.

Increasingly, vaginal sparing surgery is practised wherever it is consistent with safety and achievement of the primary goal of cancer clearance. Other issues of body image particularly with a conduit may also impact. However, with counselling, use of appropriate stomal therapy and with an understanding partner, most problems may be worked through.

Sexual dysfunction in women has many causes. These causes may be physical, psychological or a combination of both. Sexual dysfunction can be caused through the normal aging process (very common in older women), menopause. This is thought to be from a decrease in oestrogen and testosterone levels and also a loss of blood supply to the genital area. Common side effects include; loss of desire, reduced responsiveness and low sexual desire.

Vaginal atrophy or thinning of vaginal wall may cause drying of tissues and irritation especially with sexual intercourse.

Other causes of sexual dysfunction may be due to illnesses such as diabetes, high blood pressure or vascular disease. It is definitely affected by pelvic surgery which effects the blood supply to the clitoris and potential nerve damage to the surrounding structures.

When the bladder is removed in women there may also be removal of surrounding structures such as cervix, uterus, anterior vaginal vault and also urethra and ovaries. Some women may have partial sparing surgery but this will depend on the extent of their cancer.
The most common symptoms experienced by women who have had a cystectomy are; diminished ability or inability to achieve orgasm, decreased lubrication, decreased sexual desire and pain experienced during sexual intercourse.

It is very common to feel a little nervous when resuming sexual activity after your surgery.

It is important to keep the lines of communication open. There is no rush to get straight back into sexual intercourse. Having a plan and taking it slowly will ensure both you and your partner are ready for the next step. Remember you can both be sexually pleasured without having intercourse!!!

There are professionals who specialise in this area if you feel you need assistance. Speak to your health professional for contact details.

**Treatment options**

**Vaginal dryness, irritation:** Discuss with your GP to prescribe potential use of a low dose oestrogen cream (if appropriate).

**Personal Lubricants:** There are many choices to use some are water or silicone based, or you may prefer a natural oil such as almond or olive.

**Shortened vagina:** The use of a foam ring on the base of your partner’s penis will reduce the depth of penetration

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**References Pgs 32 & 33**


7. FOR FAMILIES & FRIENDS

The diagnosis of a family member or a dear, dear friend with bladder cancer can be a deeply upsetting event. Thoughts about that person, and what they are going through become ever-present, as you go through the cancer journey with your spouse, sibling or lifelong friend. One good way of providing support is to try to understand each stage of the treatment, in order to appreciate what the patient needs from their nearest and dearest.

**Initial Tests**
Coming home from the GP, after being told there is a “problem in your waterworks” that needs URGENT further investigation, is not fun. All those “what if’s” run through a person’s mind. They might think “is this going to kill me?” It’s a difficult, gut-churning, stressful time. They might want to talk about it, and they might not.

So family and friends… Tread carefully. Don’t push too hard. Listen, love. Hugs are good. Be positive... It might not be cancer... It might be very early stage and easily cured... you need to be loving and upbeat.

**First Diagnosis**
OK. It’s confirmed. Bladder cancer. And yes... it can kill you. Emotions range wildly from being totally devastated right through to being elated that “at least I know the situation now”.

Not much anyone can do from here until all tests are done. The patient will most likely be referred to a specialist and undergo urine tests, blood tests, ultrasounds, scans and/or X-Rays. Friendly company at these appointments can make a huge difference to stress levels.

**Complete Diagnosis and Treatment Plan**
Once the specialist has all the results there will be an appointment to discuss the situation. The patient might want to do this alone, or with support. Loved ones should make a point of being available if asked. It’s a big meeting.
Leaving this meeting can be either positive, if the diagnosis is an easily treatable, early stage cancer, or it can be very tough, if the disease is more advanced. There is a lot of deep thinking time here for patients who need to make choices.

There will be lots of questions, internet searching, appointments with continence nurses, discussions with other patients, more doctor discussions, thoughts about illness and death again, getting affairs in order, planning treatment and then the see-sawing final decisions about surgery.

Everybody involved needs lots of love and consideration, and lots of chat time too. Be prepared for moods swings, tears, and loving. It’s a rollercoaster so hold each other’s hands.

**Chemo/BCG treatments**
As is well documented, these treatments have side effects that can include nausea, dizziness, pain and generally make you feel unwell. It’s great if someone can be the driver and hand-holder.

**Cystoscopy/TURBT**
These procedures are done in hospital, sometimes in one day, but most likely with a hospital stay of 2-3 nights. Of course you will be restricted to hospital visiting hours in most cases. It’s great to adhere to these times as the hospital staff have strict routines, and patients will be ready to see you.

After the procedure, your Doctor will have a chat about what the medical team saw and what they took out. Again, a wait for test results on the tissue is on the cards.

Getting home and back into the normal routine shouldn’t take long. Some patients bounce back immediately. Others are sore for a week or two and take time to recover. Blood and blood clots in urine is normal as the bladder heals.
**Cystectomy Surgery**
To remove the bladder is a big deal... It’s very serious surgery of many hours, with a long recovery.

While the patient is in hospital, stick to the visiting hours. After surgery, the doctors and nurses will be very vigilant and caring, as post surgical recovery begins. The doctors want to see the patient start to drink and produce urine; have a bowel movement; start eating well; see wounds begin to heal; keep an eye out for infection... And after a week or so... All going well... the patient will go home to start rehab and recovery.

**Going Home**
Once the patient comes home from major bladder surgery, family and friends will need to use all their love and compassion, laughter and tears, encouragement and empathy to aid recovery. It can be a great family time, with lots of get togethers, feasts with family treats, hugging, loving, sharing, being together. Everyone is buoyed by “beating cancer”.

Don’t forget to make sure the patient gets plenty of rest too. Encourage small daily walks together, slowly at first.

And there will be new challenges for the patient around urination, that can be confronting, so be ready for that.

**Rehab & Recovery**
The many different ways of treating bladder cancer mean there are also many paths to a full recovery. For Chemo and BCG, it is often many months of treatment. Cystoscopy and TURBT can be quite fast recovery. The bigger cystectomy and bladder replacement operations take a longer recovery period with quite a lot of rehabilitation learning new daily processes to get rid of waste urine.

It’s also mentally challenging to learn a new way to urinate after so many years doing it normally. And often diarrhea is a part of recovery as well, so lots of toilet time for the patient is required.
Bladder Cancer Support Groups and connecting with others
In most states and territories there are cancer support groups. Also, there is an ability with cancer connect programs to talk to patients having undergone various treatments for bladder cancer.

Urologists may have some patients who are willing to share their experiences over the phone or over a coffee. This can be a more intimate way to discover what lies ahead – before and after surgery. And sometimes fellow hospital patients can become lifelong companions.

Survivorship – getting on with living
Survivorship is one of the newest aspects of cancer care as health professionals began to realize that the impact on patients may persist despite a “cure”.

As time goes by, the patient learns to do all the new things required to get on with life, and the new processes just become new daily habits. For many patients there are ongoing challenges with incontinence, skin irritations, stoma or Neobladder blockages, infections, self confidence, and more.

More love & support required by friends and family. Rest and relax together. A positive attitude, love, laughter and support – excellent medicine! Sunshine is great too!

BE VIGILANT!
Yes, Bladder Cancer can be a deadly disease, especially if it “escapes the bladder” and moves to other parts of the body. It can return years later. Make sure to keep the checkups going!

THE STORIES OF ACTUAL BLADDER CANCER PATIENTS ARE AVAILABLE AT:
WWW.BLADDERCANCER.ORG.AU-STORIES
There are many people who will likely be involved in the bladder cancer journey, from general practitioner right through to many specialists. Thankfully, most patients with bladder cancer will only ever need to be cared for by their GP, urologist and nurses. But as cases get more complex then more experience is required.

Cancer care today consists of a multi-disciplinary team. Often a particular case will be discussed at a multi-disciplinary meeting or “MDM“. This will help guide the treatment and ensure that all of the oncology disciplines hear, think about and discuss the best plan of management for each unique case (personalised medicine).

The Urology Nurse Specialist and Nurse Practitioners
Urology nurses form an incredibly important part of the treatment team. Such nurses have experience and training in urology and can offer the highest standards in the practice and development of urological nursing and urological patient care. They act as educators, counsellors and practically manage many aspects of bladder cancer treatment – from the administration of BCG to counselling on sexual matters.

All large hospitals will have access to a urology nurse specialist and many urology practices now have nurses in the consulting rooms. There are also nurses attached to the surgical and urology wards of hospitals who perform a variety of valuable tasks at the front line and behind the scenes.

There are even now some urology nurse specialists who, as Nurse Practitioners, are able to write prescriptions for some medications.

Very often a urology nurse will be your first point of contact and they will be involved from diagnosis right through all of your treatment and surveillance – often for many years. (http://www.anzuns.org).
Stomal Therapists
A stoma is created when a person undergoes a surgical procedure which results in a section of the bowel being brought to the surface of the abdominal wall. The bowel is opened and formed into a stoma, which will discharge urine in the case of an ileal conduit – but they can also pass faecal matter depending upon the type of surgery. A collection pouch is fitted over the stoma to collect the material coming through this alternative elimination site.

Stomal therapists (stomal therapy nurses) are registered nurses who have undergone additional training to be recognised as nurse specialists in the field. Their role is to provide comprehensive nursing care for patients who have had, or are about to have, stoma formation – they also have expertise in caring for wounds or fistulae (wounds that consistently discharge matter).

If radical cystectomy is to be performed, patients will normally meet a stomal therapist before surgery. The therapist will explain what a stoma is, what appliances will be used and measure the correct place(s) where the stoma will be placed (sited). (http://www.stomaltherapy.com)

There are excellent resources available for patients. The Australian Council of Stoma Associations Inc. represents, at a national level, the interests of over twenty regional Stoma Associations located throughout Australia. (http://www.australianstoma.com.au)

They provide liaison with the Australian Government in relation to the Stoma Appliance Scheme, coordinate ostomy related support services throughout Australia, provide advocacy for persons living with a stoma in Australia and publish the national journal Ostomy Australia and a general ostomy information booklet A Beginning Not an End. We encourage visitors to explore all areas of our site to gain a better understanding of the world of “ostomy”.
Physiotherapist (pelvic floor physiotherapists)

Pelvic floor physiotherapy is important to many patients with a Neobladder just as it is for men following radical prostatectomy. Of course men having a cystectomy also have their prostates removed so this is not surprising. There are three main goals of Physiotherapy:

- To strengthen the pelvic floor so that stress incontinence is minimised (leakage of urine when straining/coughing/sneezing). This requires pelvic floor exercises.
- To train the Neobladder to gain capacity over time by filling against an ever strengthening pelvic floor.
- To learn techniques to help empty the Neobladder.

It is important you seek out a physiotherapist trained to deal with a Neobladder and the pelvic floor. Your urologist will direct you to the appropriate person (https://www.physiotherapy.asn.au)

There are also good resources available to help control your continence particularly early on such as with the Continence Foundation. (http://www.continence.org.au)

Other allied health experts can contribute to some aspects of bladder cancer treatment and care, including:

- Dietitians
- Counsellors
- Sexual therapists
A staging system is a standard way for the cancer care team to describe how far a cancer has spread based on 3 key pieces of information:

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>T</td>
<td>Describes how far the main (primary) tumor has grown through the bladder wall and whether it has grown into nearby tissues.</td>
</tr>
<tr>
<td>N</td>
<td>Indicates any cancer spread to lymph nodes near the bladder. Lymph nodes are bean-sized collections of immune system cells, to which cancers often spread first.</td>
</tr>
<tr>
<td>M</td>
<td>Indicates whether or not the cancer has spread (metastasised) to distant sites, such as other organs or lymph nodes that are not near the bladder.</td>
</tr>
</tbody>
</table>

Numbers or letters appear after T, N, and M to provide more details about each of these factors. Higher numbers mean the cancer is more advanced.

**T Categories for Bladder Cancer**

The T category describes how far the main tumor has grown into the wall of the bladder (or beyond).

The wall of the bladder has 4 main layers.

1. The innermost lining is called the urothelium or transitional epithelium.
2. Beneath the urothelium is a thin layer of connective tissue, blood vessels, and nerves.
3. Next is a thick layer of muscle.
4. Outside of this muscle, a layer of fatty connective tissue separates the bladder from other nearby organs.

Nearly all bladder cancers start in the urothelium. As the cancer grows into or through the other layers in the bladder, it becomes more advanced.
<table>
<thead>
<tr>
<th><strong>TX</strong></th>
<th>Main tumor cannot be assessed due to lack of information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>T0</strong></td>
<td>No evidence of a primary tumor</td>
</tr>
<tr>
<td><strong>Ta</strong></td>
<td>Non-invasive papillary carcinoma</td>
</tr>
<tr>
<td><strong>TiS</strong></td>
<td>Non-invasive flat carcinoma (flat carcinoma in situ, or CIS)</td>
</tr>
<tr>
<td><strong>T1</strong></td>
<td>The tumor has grown from the layer of cells lining the bladder into the connective tissue below. It has not grown into the muscle layer of the bladder.</td>
</tr>
<tr>
<td><strong>T2</strong></td>
<td>The tumor has grown into the muscle layer.</td>
</tr>
<tr>
<td><strong>T2a</strong></td>
<td>The tumor has grown only into the inner half of the muscle layer.</td>
</tr>
<tr>
<td><strong>T2b</strong></td>
<td>The tumor has grown into the outer half of the muscle layer.</td>
</tr>
<tr>
<td><strong>T3</strong></td>
<td>The tumor has grown through the muscle layer of the bladder and into the fatty tissue layer that surrounds it.</td>
</tr>
<tr>
<td><strong>T3a</strong></td>
<td>The spread to fatty tissue can only be seen by using a microscope.</td>
</tr>
<tr>
<td><strong>T3b</strong></td>
<td>The spread to fatty tissue is large enough to be seen on imaging tests or to be seen or felt by the surgeon.</td>
</tr>
<tr>
<td><strong>T4</strong></td>
<td>The tumor has spread beyond the fatty tissue and into nearby organs or structures. It may be growing into any of the following: the stroma (main tissue) of the prostate, the seminal vesicles, uterus, vagina, pelvic wall, or abdominal wall.</td>
</tr>
<tr>
<td><strong>T4a</strong></td>
<td>The tumor has spread to the stroma of the prostate (in men), or to the uterus and/or vagina (in women).</td>
</tr>
<tr>
<td><strong>T4b</strong></td>
<td>The tumor has spread to the pelvic wall or the abdominal wall.</td>
</tr>
</tbody>
</table>

Bladder cancer can sometimes affect many areas of the bladder at the same time. If more than one tumor is found, the letter m is added to the appropriate T category.
**N Categories for Bladder Cancer**
The N category describes spread only to the lymph nodes near the bladder and those along the blood vessel called the common iliac artery. These lymph nodes are called regional lymph nodes.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>NX</td>
<td>Regional lymph nodes cannot be assessed due to lack of information.</td>
</tr>
<tr>
<td>N0</td>
<td>There is no regional lymph node spread.</td>
</tr>
<tr>
<td>N1</td>
<td>The cancer has spread to a single lymph node in the true pelvis.</td>
</tr>
<tr>
<td>N2</td>
<td>The cancer has spread to 2 or more lymph nodes in the true pelvis.</td>
</tr>
<tr>
<td>N3</td>
<td>The cancer has spread to lymph nodes along the common iliac artery.</td>
</tr>
</tbody>
</table>

**M Categories for Bladder Cancer**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>M0</td>
<td>There are no signs of distant spread.</td>
</tr>
<tr>
<td>M1</td>
<td>The cancer has spread to distant parts of the body. (The most common sites are distant lymph nodes, the bones, the lungs, and the liver.)</td>
</tr>
</tbody>
</table>
**Stages of Bladder Cancer**

Once the T, N, and M categories have been determined, this information is combined to find the overall cancer stage. Bladder cancer stages are defined using 0 and the Roman numerals I to IV (1 to 4). Stage 0 is the earliest stage, while stage IV is the most advanced.
10. GLOSSARY

**ADJUVANT THERAPY:** Treatment given just after the main or primary treatment of the cancer. It is used to ‘mop up’ any potential remaining disease (e.g. chemotherapy).

**BCG:** Bacillus Calmette–Guérin vaccine is primarily used against tuberculosis, but is also effective to treat bladder cancer by stimulating the immune system (immunotherapy).

**BONE SCAN:** Used to image specifically bones to find any tumor deposits.

**CARCINOMA:** A cancer that begins in a tissue that lines the inner or outer surfaces of the body.

**CATHETER (urinary):** A latex, polyurethane, or silicone tube known as a urinary catheter is inserted into a patient’s bladder via the urethra.

**CIS:** Carcinoma in situ (CIS), also known as in situ neoplasm, is a group of highly abnormal cells growing on the surface so is noninvasive but still dangerous.

**CT (computed tomography):** Imaging done using low doses of radiation to form pictures of the internal structures that help diagnose disease stage.

**CYSTECTOMY:** A medical term for surgical removal of all (radical) or part (partial) of the urinary bladder.

**CYSTOSCOPY:** Endoscopy (looking inside) of the urinary bladder via the urethra. It is carried out with a cystoscope.

**DIVERTICULUM:** A bladder diverticulum is a pouch in the bladder wall that a person may either be born with (“congenital”) or develop later in life (“acquired”).

**ENDOSCOPE:** An illuminated slender optical instrument used to look deep into the body in procedures called endoscopy. (e.g into bladder termed cystoscopy).

**HISTOPATHOLOGY:** The microscopic examination of tissue in order to study the manifestations of disease.

**ILEAL CONDUIT:** Urinary diversion to a stoma and a urine collection bag.

**INDIANA POUCH:** Same as Continent Cathererisable Pouch on page 20

**INTRAVESICAL THERAPY:** The doctor puts a liquid drug directly into the bladder (through a catheter) rather than giving it by mouth or injecting it into a vein.

**INTROMITTENT ORGAN:** General term for an external organ of a male organism that is specialised to deliver sperm during copulation – a penis.

**LYMPH NODE:** Small, bean-shaped glands throughout the body. They are part of the lymph system, which carries fluid (lymph fluid), nutrients, and waste material between the body tissues and the bloodstream.

**METASTASIS:** The spread of a cancer or other disease from one organ or part of the body to another without being directly connected with it.

**MITROFANOFF PROCEDURE:** Similar to Continent Cathererisable Pouch on page 20 also known as the Mitrofanoff Appendicovesicostomy or a Continent Urinary Diversion.

**MRI (magnetic resonance imaging):** Uses the power of magnets to form pictures of the internal structures that help staging disease.
NEOADJUVANT THERAPY: Treatment given as a first step to shrink a tumor before the main treatment. An example of neoadjuvant therapy is chemotherapy.

NEOBLADDER: A replacement bladder fashioned from bowel tissue.

ONCOLOGIST: Oncology is the study of cancer. An oncologist is a doctor who treats cancer.

OSTOMY: Refers to the surgically created opening in the body (stoma) for the discharge of body wastes.

PET-CT (positron emission tomography): similar to a CT scan but uses glucose to find hungry cancer cells and so is a functional study.

POUCH – Catheterisable: Internal urine collection pouch connected to an external stoma for urine disposal.

RADICAL CYSTECTOMY: The removal of the whole bladder and nearby tissues and organs.

SALVAGE THERAPY: A treatment that is given after the cancer has not responded to other treatments.

SQUAMOUS CELL CARCINOMA (SCC): Also known as squamous cell cancer, is cancer that begins from squamous cells, a type of skin cell.

STAGING: Cancer staging is the process of determining the extent to which a cancer has developed by spreading.

STENT: A thin tube sitting in the ureter that helps drain urine from the kidney to the bladder (or conduit pouch or Neobladder). Often temporary to help healing.

STOMA (urinary): An external opening in the abdominal wall to drain urine from the body.

TCC (Transitional Cell Carcinoma): Also known as urothelial carcinoma, a type of cancer that occurs in the urinary system (kidney, urinary bladder, and urethra).

TUMOUR: A swelling of a part of the body, caused by an abnormal growth of tissue, whether benign or malignant.

TURBT: Trans Urethral Removal of Bladder Tumor. Surgical procedure to remove cancer cells using a cystoscope.

URETER: The tube by which urine passes from the kidney to the bladder.

URETHRA: The tube that connects the urinary bladder to the urinary opening for the removal of fluids from the body. In males, the urethra travels through the intromittent organ. In females, the urethra is shorter and emerges at the female external urethral orifice above the vaginal opening.

UROLOGY/UROLOGIST: The branch of medicine that focuses on surgical and medical diseases of the male and female urinary tract system and the male reproductive organs. The organs under the domain of Urologists include the kidneys, adrenal glands, ureters, urinary bladder, urethra, and the male reproductive organs (testes, epididymis, vas deferens, seminal vesicles, prostate, and penis).

UROTHELIAL CARCINOMA: see TCC.

UROTHELIUM: The tissue that lines much of the urinary tract. Urothelium consists of approximately 3-5 cell layers, accompanied by a thick layer of protective glycoprotein.
Bladder Cancer Australia Charity Foundation (BCACF) was formed in 2015 to campaign for Awareness, Screening, Treatment and Research for Bladder Cancer.

BCACF is a fully registered Australian charity ACN: 59119773067, with full tax deductibility status for donations.

The Foundation currently receives no government funding.

You can assist our work by:

- Making a tax deductible donation
- Signing our online petition

Just visit our web site at: www.bladdercancer.org.au

Thank You

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ANZ Facebook Support Groups

Two great patient and family driven private groups to look for on Facebook:
* Mens Bladder Cancer and Prostate Support Group
* Bladder Cancer Support - Australia / New Zealand
Every case and every patient is different. The information in this publication is of a general, non-specific nature. It is not intended, and should not be used as a substitute for the advice of qualified medical professionals.

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