

Bladder

1.Introduction

Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells: to enable us to grow, to replace worn out cells, or to heal damaged cells after an injury. Certain genes control this process. All cancers are caused by damage to these genes. This damage usually happens during our lifetime, although a small number of people inherit a damaged gene from a parent when they are born. Normally, cells grow and multiply in an orderly way. However, damaged genes can cause them to behave abnormally. They may grow into a lump, which is called a tumour. Tumours can be benign (not cancerous) or malignant (cancerous). Benign tumours do not spread outside their normal boundary to other parts of the body.

A malignant tumour is made up of cancer cells. When it first develops, this malignant tumour may be confined to its original site, a cancer in situ (or carcinoma in situ). If these cells are not treated they may spread beyond their normal boundaries and into surrounding tissues (invasive cancer). For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This is called angiogenesis.

Sometimes cells move away from the original (primary) cancer and invade other organs. When these cells reach a new site they may continue to grow and form another tumour at that site. This is called a secondary cancer or metastasis.

In some cancers, it is the body's blood cells, which multiply abnormally. These cancers are called leukaemia, myeloma and lymphoma.

The Bladder

The bladder is a hollow, muscular, balloon-like organ that stores urine. It sits in the lower part of the abdomen. Urine consists of water and waste products not needed by the body.

The bladder is lined with a membrane which stops the urine being absorbed back into the body. The cells of this membrane are called transitional cells or urothelial cells, and the membrane lining is called the urothelium.

The kidneys produce urine, which is carried to the bladder by tubes called ureters. The bladder then stores the urine until it is full enough to empty it through a tube called the urethra, which passes urine from the body.

In women, the urethra is a very short tube immediately in front of the vagina (birth canal). In men the tube is longer and passes through the prostate gland and the penis.

Bladder Cancer

Nearly all cancers of the bladder are found in the urothelium (lining of the bladder). These are called transitional cell cancers. They come in a wide range of forms and can behave in very different ways.

A large number of transitional cell cancers grow on the inside lining of the

bladder. These are called superficial cancers. There are two types of superficial tumours: carcinoma in situ, which are flat and non-invasive, and papillary, which stick out from the lining like mushrooms. Sometimes transitional cell cancers spread into the wall of the bladder. These are called invasive cancers. Squamous cell carcinomas and adenocarcinomas are less common bladder cancers. These types are likely to spread to deeper layers of the bladder.

2. Causes of bladder cancer

Several factors are known to increase the risk of developing bladder cancer.

- **Cigarette smoking** is the most important factor. Some chemicals found in cigarette smoke are known to cause bladder cancer.
- The other main cause of bladder cancer is exposure to certain **chemicals** at work, for example, some used in dyeing in textile and rubber industries. It can take many years after exposure to these chemicals before bladder cancers start to develop.
- Frequent **cystitis** (inflammation of the bladder), caused by repeated bacterial infections and bladder stones, has been linked with bladder cancer, but does not necessarily cause it.
- In Egypt and Asia, infection with the parasite **schistosoma** (bilharzia) is associated with bladder cancer.

How common is bladder cancer?

In Malaysia, more than 534 people are diagnosed with this type of cancer each year. Bladder cancer occurs most commonly from the age of 55 and is twice as common in men as in women. Bladder cancer is very rare in men and women under 40 years of age.

The most common symptom of cancer of the bladder is haematuria (blood in the urine). This usually occurs suddenly and is generally not painful. The blood may be present one day and disappear the next, but eventually it does come back. Sometimes blood clots can form, and these may cause painful muscle spasms in the bladder. The amount of blood in the urine is not related to the extent of the cancer. Sometimes blood is present in only microscopic amounts: bladder cancer is often discovered 'by accident' following routine tests.

Some people may have a burning feeling when they pass urine, and need to pass urine often. These are also symptoms of any bladder irritation and usually mean an infection rather than cancer. However, if it persists and is not cleared up by antibiotics then further tests may be necessary.

If you do see any blood in your urine, you must have it checked by your doctor as soon as possible. Remember that this symptom is common to many conditions other than cancer, for example kidney or bladder stones, and enlargement of the prostate gland in men.

What doctors and other health professional will I see?

Your general practitioner will examine you and refer you for initial tests to confirm whether or not you have cancer. This can be a worrying and tiring time, especially if you need to have several tests. If a diagnosis of cancer is made, your general practitioner will also refer you to an urologist (specialist surgeon) who will advise you about treatment options.

You should expect to be cared for by a team of health professionals from the relevant major disciplines, in a treatment centre that has available all means of diagnosis and treatment.

Specialists and other health professionals who care for people with bladder cancer may include:

- **urologists**: surgeons who specialise in diseases of the urinary tract and are responsible for diagnostic tests including biopsies and other surgical procedures
- **medical oncologists**: who are responsible for chemotherapy
- **radiation oncologists**: who are responsible for radiotherapy
- **nurses**: who will assist you through all stages of your hospitalisation and cancer experience
- **stomal therapy nurses**: who help people care for a urostomy
- **dieticians**: who will recommend the best diets to follow while you are in treatment and recovery
- **social workers, physiotherapists and occupational therapists**: who will advise you on support services and help you to resume normal activities.

3. How is bladder cancer diagnosed?

If your doctor suspects that you have bladder cancer, he or she will recommend some of the following tests.

Urine test

Your doctor will ask you to provide a urine sample. The urine sample will be sent to a laboratory to be checked under a microscope for any cancer cells.

Physical examination

The doctor will examine your pelvis and other organs. A doctor may do a more extensive physical examination later, in a hospital, while you are under anaesthetic.

Blood tests

The doctor will take a blood sample to check your general health, your blood count (the numbers of different cells in your blood) and to see how well your kidneys are working.

Intravenous pyelogram (IVP)

An intravenous pyelogram (IVP) shows up abnormalities in the kidneys, bladder and the rest of the urinary system. A dye is injected into a vein, usually in the arm, and goes through the bloodstream to the kidneys. The doctor can watch the dye move around the body on an x-ray screen and pick up any abnormalities. The dye will probably make you feel hot and flushed for a few minutes, but this feeling gradually disappears. You may feel some

discomfort in your abdomen, but this will only be temporary. You should be able to go home as soon as the test is over. It takes about an hour.

Liver and abdominal ultrasound scan

In this test, sound waves are used to make up a picture of the inside of your abdomen and the liver. Before your test you will be asked to drink plenty of fluids so that your bladder is full and a clear picture can be seen. Once you are lying comfortably on your back, a special gel is spread over your abdomen. A small device, like a microphone, is passed over the area. The echoes are converted into a picture by a computer. This is a completely painless procedure and takes about 15-20 minutes.

Cystoscopy and biopsy

The most important test for diagnosing cancer of the bladder is called a cystoscopy. It can be done while you are under a general anaesthetic but in most cases cystoscopy is done under local anaesthetic. Some jelly containing anaesthetic is inserted into the urethra. The test is carried out using a small, flexible telescope called a cystoscope that allows the doctor to look at the lining of the bladder and urethra. The cystoscope is gently passed through the urethra and into the bladder. If any abnormality that may be a bladder cancer is seen, the bladder has to be examined under a general anaesthetic. A sample of tissue is removed from the inside or lining of the bladder. This is called a biopsy. The samples are then examined in a laboratory under a microscope to see if there are any cancer cells. If an obvious cancer is found during this examination it can be removed at the same time. See the Treatment section later in this web site section.

Further tests

If the tests show that you have bladder cancer, the urologist may want you to have further tests to see if the cancer has metastasised (spread). Many bladder cancers have a low chance of spreading, so people with these bladder cancers may not need further tests. These tests also help the doctor to decide on the best type of treatment for you.

Computerised tomography (CT) scan

A CT scan is a special type of x-ray that gives a three-dimensional picture of the organs and other structures (including any tumours) in your body. These images are used to see if the cancer has spread beyond the bladder.

CT scans are usually done at a hospital or a radiology clinic. It usually takes about 30-40 minutes to complete this painless test.

You will not be able to eat or drink anything before the scan except a special liquid that helps outline the bowel. You will also have an intravenous injection of dye that helps outline the kidneys, ureter and bladder. You will be asked to lie flat on a table while the CT scanner, which is large and round like a doughnut, rotates around you. Most people are able to go home as soon as their scan is over.

Radioisotope bone scan

A radioisotope scan may be done for some cancers, to see if any cancer cells have spread beyond the bladder and into the bones. For this test, a tiny

amount of a radioactive dye is injected into a vein, usually in the arm. You will be scanned by a machine that measures tiny amounts of radioactivity. The doctor can tell if there has been any spread of the disease, as a larger amount of radioactivity is found in areas of bone affected by cancer cells. After the dye has been injected you will have to wait a few hours before having the scan, so you may want to take a magazine or book with you to pass the time. The amount of radioactivity used is small and the radioactivity disappears from your body within a few hours. You will be advised to avoid contact with pregnant women and younger children for the rest of the day, and drink plenty of fluids.

Chest x-ray

A chest x-ray uses low doses of radiation to check for abnormal areas in the chest. It takes only a few minutes and is painless and safe. This is taken to check that your lungs and heart are healthy.

Staging the disease

The tests described on previous web pages show whether you have cancer. They will also show where the primary cancer is and whether the cancer cells have spread to other parts of your body (this is known as metastasis). This helps your doctors 'stage' the disease so they can work out the best treatment for you.

The staging system used for bladder cancer is known as the 'TNM system' (T=tumour, N=nodes, M=metastases).

- **T** followed by a number between 1 and 4 shows how far the cancer has invaded the bladder wall and nearby tissues. A higher number after the T (for example, T3 or T4) means it has spread further.
- **N** plus a number from 0 to 3 describes whether the cancer has spread to lymph nodes near the bladder and, if so, the amount of cancer in the nodes. Higher numbers are used for nodes that are more seriously affected by the cancer.
- **M** followed by I shows that the cancer has metastasised (spread) to other organs or to lymph nodes that are not near the bladder. MO means the cancer has not spread in this way.

Doctors combine this information to determine the stage of the cancer, from Stage 1 (I) to Stage 4 (IV). For example, a cancer assessed as T1, N0, M0 (tumour contained within the bladder, lymph nodes not affected and no metastasis) would be called a Stage I cancer.

Ask your doctor to explain the stage of your cancer in a way you can understand. This will help you to choose the best treatment for your own situation.

4. Treatment

The type of treatment you choose will depend on whether the cancer is superficial (only in the lining of the bladder) or invasive (has spread into the wall of the bladder and beyond). Your specialist will discuss your treatment options with you.

Treatment for superficial bladder cancer

Superficial bladder cancers are treated with surgery and/or immunotherapy or, sometimes, chemotherapy.

Surgery: transurethral resection

Superficial cancers are removed in a procedure called transurethral resection (TUR). You will have a general anaesthetic. The doctor will pass a cystoscope, a slender tube with a lens and a light, through the urethra and into the bladder. The cystoscope enables the doctor to see inside the bladder. Each tumour is removed. The doctor may use electrosurgery. The area around the tumour is cauterised (burned) to prevent excessive bleeding. This sounds severe, but is a safe and common way of removing diseased tissue. Several tumours can be treated at the same time.

After this treatment, follow-up cystoscopies are needed at regular intervals (usually every three to four months at first) because the cancer can come back. Those follow-up cystoscopies, which do not require cautery, can be carried out in the outpatients department under local anaesthetic. If there is any recurrence of the cancer, it can usually be surgically removed while it is still in the early stages. This will require a separate cystoscopy under general anaesthetic.

Some people receive immunotherapy or chemotherapy instead of, or as well as, surgery.

Immunotherapy: BCG

Immunotherapy (or biological therapy) is the use of substances that are naturally produced within the body to encourage the immune system to fight disease.

A vaccine called BCG, placed in the bladder, has been shown to be an effective treatment for superficial bladder cancers. BCG contains live tuberculosis bacteria, so strict precautions must be followed.

The exact way in which this treatment works is not fully known, but it seems that the vaccine can set up a reaction in the bladder which triggers the body's immune system to reduce or eliminate cancer cells.

The treatment takes place in the urology or oncology outpatients department. It is given once a week, for six weeks. The vaccine is given directly into the bladder through a catheter. Each treatment lasts two hours and during this time the BCG treatment is working on the bladder lining to set up an immune reaction in your body. For the next six hours, when you pass urine, you should sit rather than stand (men as well as women) to avoid splashing on the seat or floor as your urine will still contain BCG.

Men having this treatment can transmit BCG during intercourse. To protect your partner from coming into contact with BCG, you should not have sexual intercourse for 48 hours after each treatment. Use a condom if you have sexual intercourse at other times during the six weeks of treatment. You should also use a condom for sexual intercourse for six weeks after treatment has ended. If you have questions about this, ask your doctor.

You will need to drink more liquid (not alcohol) in the 24 hours after treatment, to help flush out the vaccine. It is important to let your doctor know about any other drugs you are taking, because if you are taking other drugs that suppress your immune system, they may interfere with how well your bladder cancer responds to this treatment. The treatment may be repeated at intervals over the next two years. Your doctor will arrange this with you if it is necessary in your case.

Side effects of immunotherapy

During the treatment you will probably experience side effects such as blood in your urine, needing to pass urine often and pain when you pass urine. These side effects are to be expected and they almost always settle down on their own. However if you experience fever, pain in your joints, cough, skin rash or severe tiredness, you should tell your doctor. These fever and flu-like symptoms can be treated with the drug isoniazid.

Intravesical chemotherapy

Chemotherapy is the use of special anti-cancer (cytotoxic) drugs to destroy the cancer cells. They work by disrupting the growth of cancer cells. Chemotherapy may be helpful to some patients with cancer of the bladder. The drugs can be given directly into the bladder, or intravenously (by injection into a vein).

Chemotherapy is occasionally used like BCG immunotherapy (above): chemotherapy drugs are placed in the bladder, near the tumour. Chemotherapy given directly into the bladder is called intravesical chemotherapy. The drugs are passed through a catheter and into the bladder. Giving chemotherapy in this way puts the drugs in direct contact with the tumour and the lining of the bladder. It also reduces side effects, as very little gets into the bloodstream to affect the rest of the body. The drugs may be given as one injection, or a course of weekly injections for about six weeks.

Side effects of intravesical chemotherapy

If you receive chemotherapy directly into the bladder, you may experience cystitis and may need to pass urine more often than normal.

Treatment for invasive bladder cancer

Surgery is the most common form of treatment for invasive bladder cancer. Chemotherapy and/or radiotherapy are an alternative treatment for invasive bladder cancer. Part or the entire bladder may need to be removed. Sometimes a new 'bladder' is made.

Cystectomy

Sometimes the cancer may be too large to be removed by the cystoscope, or may have started to grow through the bladder wall. In these cases, it may be necessary to remove part or the entire bladder.

If part of the bladder is removed, the operation is called a partial cystectomy. After this operation you will be able to pass urine as usual, but as your bladder will be smaller and therefore hold less urine, you will need to pass urine more often.

If the entire bladder is removed, in an operation called a radical cystectomy, a

new storage place for urine will need to be created.

If the cancer has started to spread beyond the bladder, the doctor can often stop further spread by removing the bladder and organs close to the bladder. The operation is called a radical cystectomy. In women, the uterus (womb), ovaries and Fallopian tubes and sometimes the part of the vagina that contains the urethra may also be removed. If this happens, you will undergo menopause and be unable to have children and will probably experience menopausal symptoms, for example, hot flushes. If this is of concern, talk to your doctor before surgery about the options that may be available to you. In men, the prostate gland and sometimes the urethra need to be removed, since the cancer can recur in these organs. Removing the bladder can affect the nerves needed to get an erection, so your sex life may change. See the later section that discusses sexuality and cancer.

After the operation

When you wake up from the operation you will have several tubes in place. You will have an intravenous drip to give you fluid as well as medication. You will have tubes in your abdomen to drain away fluid from the operation site. You will probably feel very tired for some weeks. You will have some pain or discomfort in the areas where organs were removed and you have stitches. Tell the doctor or nurse if you have pain and don't wait for it to become severe before asking for painkillers. You will be in hospital for 10-14 days. You may see a physiotherapist, who will explain how you may begin exercising again. If you have a stoma (see below), a specially trained stomal therapy nurse will explain how to care for it and tell you about the various support services available.

Urostomy

The most common way of providing a new storage place for urine is to form a urostomy. While you are under a general anaesthetic, the doctor will remove a piece of your small bowel, join the two ureters to one end of it and bring the other, open end out through the skin of your abdomen. This is called an ileal conduit, as the piece of small bowel (ileum) acts as a drainpipe to take the urine from the ureters and bring it to the surface of the abdomen. The bowel will be rejoined after the piece to be used for the urostomy has been removed. A flat, watertight bag is placed over the opening on the abdomen (stoma) to collect the urine. It is kept in place with a special type of glue. The bag will fill with urine in the same way as the bladder and will need to be emptied as necessary. The stomal therapy nurse will advise you how to care for your ileal conduit.

For more information, see the section towards the end of this web section titled Living with a Urostomy.

Continent urinary diversion

One alternative to the ileal conduit is the continent urinary diversion. The main advantage of this technique is that it is not necessary to wear a stoma bag. During the operation, a pouch is formed in the abdomen, using a piece of bowel. This pouch holds the urine. A small catheter can be passed through the stoma into the pouch about four or five times a day to empty the urine. This is called self catheterisation. With good teaching and practice most

people cope very well with self-catheterisation and care of their stoma. Continent urinary diversions may not be suitable for everybody, so you would need to discuss this with your own doctor.

Bladder reconstruction

Another way of providing a storage place for urine is by using a piece of the bowel to construct a completely new bladder. In most cases, it allows you to urinate as usual, without the need for a stoma or catheter. The operation is known as bladder reconstruction, and it can be achieved in a number of different ways.

Usually your doctor will remove a piece of your bowel, make it into a balloon-shaped sac and stitch it to the top of your urethra. The ureters are stitched into this new bladder so that urine drains directly into it from the kidneys. It is then possible to pass urine in the usual way through the urethra.

For some people, a catheter will still be needed occasionally to drain the bladder of urine, as the pouch doesn't empty completely. Flexing your abdominal muscles empties the new bladder, but you will need to remember to empty it, as you will have lost the nerves that tell you when your bladder is full. Sometimes this nerve loss can lead to slight incontinence, especially when you are asleep. A bladder reconstruction may affect the nerves needed for a man to get an erection, so it can affect a man's (and his partner's) sex life.

Bladder reconstruction is not suitable for everyone. Discuss this with your doctor: there is a list of questions at the end of this web section that might help.

Radiotherapy

Radiotherapy treats cancer by using radiation, usually x-rays, to kill cancer cells. These x-rays can be precisely targeted onto cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body tissues.

Radiotherapy may be used instead of surgery to treat invasive bladder cancer to try and avoid having to remove the bladder.

Sometimes chemotherapy is given in conjunction with radiotherapy so the cells are made more sensitive to the radiotherapy.

The treatment is given in a radiotherapy department. The course is usually in five sessions from Monday to Friday, with a rest at the weekend. The length of your treatment will depend on the type and size of the cancer and whether the aim is cure or relief of symptoms.

Side effects of radiotherapy

The most common side effects of radiotherapy are fatigue, skin problems and loss of appetite. It can also cause problems in the area treated. Radiotherapy to the pelvis may irritate the bowel and cause diarrhoea and soreness around the anus. It may also cause mild cystitis, and make you pass urine more often or experience a burning feeling when you pass urine. In some people, the bowel or bladder may be permanently affected by the radiotherapy. If this happens then increased bowel motions and bleeding may occur. Skin in the treatment area may become red and sore after two or three weeks of treatment. From the start of your treatment, you will need to take care

washing and avoid shaving the area or wearing clothing that rubs. Check with your doctor or nurse before using any talcs and lotions. Ask a member of your radiotherapy treatment team about how to deal with the side effects of radiotherapy.

Intravenous chemotherapy

Chemotherapy is the use of special anti-cancer (cytotoxic) drugs to destroy the cancer cells. They work by disrupting the growth of cancer cells.

Chemotherapy may be helpful to some patients with cancer of the bladder. The drugs can be given directly into the bladder, or intravenously (by injection into a vein). If the cancer has spread into the wall of the bladder, or to other parts of the body, the chemotherapy drugs are sometimes given intravenously.

Intravenous chemotherapy may be given:

- before surgery to shrink the cancer and make it easier to operate
- after surgery if it is thought there is a high risk of the cancer coming back, or
- if the cancer has already spread to other parts of the body.

This is done so that the drugs can circulate in the bloodstream and reach the cancer cells that might have spread to other parts of the body. A course of several drugs is given over a few days. The course is then repeated every few weeks for several months.

Side effects of intravenous chemotherapy

Some drugs used in chemotherapy can cause side effects. They may include feeling sick, vomiting, depression, feeling off-colour and tired, and some thinning or loss of hair from your body and head. These side effects are temporary, and steps can be taken to prevent or reduce most of them.

Some drugs can cause longer-term or permanent side effects. Steps will be taken by your doctors to monitor these effects.

Palliative treatment

Palliative treatment is treatment that relieves or soothes pain and other distressing symptoms of illness. Palliative care is available for people who experience pain and distress associated with cancer, whatever their stage of cancer treatment. It is a particularly important type of treatment for people with advanced cancer, who cannot be cured but can expect to live without undue pain and distress.

Palliative care includes pain relief using painkilling drugs and other measures. Pain is usually well controlled with oral medication. General practitioners, specialists and specialist palliative care teams in hospital play important roles in palliative treatment for people with advanced cancer. For further information, contact the Resource and Wellness Centre 03 26987300 or email: contact@cancer.org.my

Prognosis

Bladder cancer can be effectively treated if it is found early, before it spreads outside the bladder. You will need to talk with your doctor about your own prognosis. Your medical history is unique, so you will need to discuss with someone who knows your medical history what you can expect and the

treatment options that are best for you.

Making decisions about treatment

Sometimes it is difficult to make decisions about what is the right treatment for you. You may feel that everything is happening so fast that you do not have time to think things through. Some people find that waiting for test results and for treatment to begin is very difficult.

While some people feel they are overwhelmed with information, others may feel that they do not have enough. You need to make sure that you understand enough about your illness, the possible treatment and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh up the advantages and disadvantages of each treatment. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been advised.

Some people with more advanced cancer will always choose treatment, even if it only offers a small chance of a cure. Others want to make sure that the benefits of treatment outweigh any side effects. Still others will choose the treatment they consider offers them the best quality of life. Some may choose not to have treatment but to have any symptoms managed as they arise in order to maintain the best possible quality of life.

Talking with doctors

You may want to see your doctor a few times before making a final decision on treatment. The first consultation when you are told you have cancer is usually stressful and you may not remember very much. It is often difficult to take everything in, and you may need to ask the same questions more than once. You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it.

Talking with others

Once you have discussed treatment options with your doctor, you may want to talk them over with family or friends, with nursing staff, the hospital social worker or chaplain, or your own religious or spiritual adviser. Talking it over can help to sort out what course of action is right for you.

A second opinion

You may want to ask for a second opinion from another specialist. This is understandable and can be a valuable part of your decision-making process. Your specialist or local doctor can refer you to another specialist and you can ask for your records to be sent to the second-opinion doctor. You can still ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.

Taking part in a clinical trial

Your doctor may suggest that you consider taking part in a clinical trial. Clinical trials are a vital part of the search to find better treatments for cancer. Doctors conduct clinical trials to test new or modified treatments and see if they are better than existing treatments. Your doctor will only discuss a clinical trial with you if the treatments are considered to be as good as or better than

the standard treatments available. Many people all over the world have taken part in clinical trials that have resulted in improvements to cancer treatment. However the decision to take part in a clinical trial is always yours. If your doctor asks you to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What treatments are being tested and why?
- What tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other, but it will always be at least the best treatment available.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not jeopardise your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

Recovery and follow-up care

After your treatment has been completed your doctor will want you to have regular check-up cystoscopies and x-rays. These will often continue for several years. If you have any problems or notice any new symptoms in between these times, let your doctor know as soon as possible.

Sometimes you may find that your friends and family do not know what to say to you: they may have difficulty with their feelings as well. Some people may feel so uncomfortable that they avoid you. They may expect you to 'lead the way' and tell them what you need. This can be very difficult to bear and can make you feel very lonely. You may feel able to approach your friends directly and tell them what you need. You may prefer to ask a close family member or a friend to talk with other people for you.

Living with a urostomy

Some people with cancer of the bladder will need a radical cystectomy and urostomy. Most people who have a urostomy live a normal life. Many return to their jobs and take up their favourite pastimes again, including swimming. Learning to look after a urostomy, however, takes time and patience and no one expects you to cope straight away. Like anything new, it will get better with practice. Most hospitals have specially trained nurses called stomal therapy nurses, who will show you how to look after your urostomy and help you cope with any problems. You may also find it helpful to talk with someone who has already learned to live with a urostomy. Your nurse or doctor can often arrange for a volunteer to visit you and talk to you about the more personal aspects. This advice, which comes from their own experience, can be invaluable, especially in the first few months after your operation. Before your operation the doctor or nurse will carefully plan the position of your

stoma, so that your bag will stay in place whether you are sitting, standing or moving about. The stoma is usually formed on the abdomen, to the right of the navel (belly button), but there are many things that must be taken into account when planning the site. Wrinkles, scars and prominent underlying bones must be avoided, as placing the stoma near them may cause problems with leakage later on. Sometimes the stoma can be tailored to a patient's particular need, for example a golfer may prefer a left-sided stoma so that it doesn't interfere with playing his or her sport.

Taking care of the stoma

For the first few days after your operation, the nurse will look after your urostomy for you and make sure the bag is emptied and changed as often as necessary. At first your stoma will be slightly swollen and it may be several weeks before it settles down to its normal size. The stoma may also produce mucus (a thick white substance). As time passes the amount of mucus produced will lessen, but will never disappear completely. As soon as you feel ready the nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to join you at this time in case you ever need help at home. There are several types of bags or appliances available and the nurse will help you to choose one that suits you best. When you are changing your bag, it helps to allow yourself plenty of time and privacy, so that you can work at your own pace without interruptions.

Getting help

Before you leave hospital, the nurse will make sure you have a good supply of Urostomy bags. Later, you will get your supplies direct from a local stockist.

Sexuality and cancer

If you need a Urostomy you may be worried about adapting to changes in how your body looks and how you feel about your body. This is a normal reaction, as over the years we all develop an image in our minds about what our bodies look like. Although we may not be completely satisfied with that image, most people do get used to the way they see themselves. It is upsetting therefore to have that image changed permanently by a Urostomy.

You may also be very concerned about the effect it may have on your personal relationships and lifestyle. You may be worried about rejection, continuing to have sex with your partner, or starting a new relationship. Many people find that once they have summoned up the courage to talk about their fears with a partner, their minds are set at ease. Just expressing your feelings can help to clarify your fears and also gives others the opportunity to understand how you are feeling. Fears of rejection are usually unfounded. Intimate relationships are built on love and trust. New partners can be understanding and supportive if you are open and honest about your misgivings from the start.

Most modern appliances are designed to be flat and unnoticeable under clothing, but the size and site of the stoma will be the most important factor in whether or not the bag or appliance is noticeable through your clothes. The style of clothing you wear is obviously important, but many young people with

a Urostomy find that they can wear the tightest clothes without advertising that they are wearing a bag. Although you may remain conscious of your Urostomy, few other people will ever notice unless you tell them.

Damage to the nerves in the penis

Apart from the psychological adjustments, the operation may have made physical changes, which can cause problems with sex. It is often impossible to avoid damage to the nerves in the penis during the operation, although your doctor will do all he or she can to prevent nerve damage. If this has happened it may be difficult for a man to get an erection. However, it is now possible for men who have problems getting erections to be treated with injections into the penis. Oral medications like Viagra may also assist with sexual functioning.

There are two other methods. One is the use of mechanical devices to produce an erection. These are called penile prostheses and involve the insertion, under general anaesthetic, of flexible rods or thin inflatable cylinders into the penis.

The other is the use of external vacuum devices to produce erections. They are simple, painless and easy to use, and are available from sex aid shops or on prescription.

Changes to the vagina

In some women, the vagina (birth canal) may have been shortened or narrowed during the operation to remove the bladder, although the doctor will take care to leave as much of the vagina intact as possible. This can make penetrative sex difficult or uncomfortable at first. One of the best ways of overcoming this problem is to start having sex regularly and gently, as soon as you feel ready. This will gradually stretch the vagina, making it more supple, and will make sex easier and more enjoyable.

If the uterus has been removed in order to treat any spread of the cancer, it can make a woman feel she has lost a part of her female identity. Talking to your doctor about any problems will help to bring fears and worries into the open. If you want, he or she can refer you to a specialist in sexual problems, or a trained counsellor, for advice and support.

Talking about sexual problems

You may find it difficult or embarrassing to talk about any sexual problems you may have. However, most doctors are very understanding, and even if they are unable to help they can refer you to a doctor or therapist who specialises in sexual problems. These specialists can offer emotional support and advice on how to cope with sexual difficulties and related problems. It can be helpful to remember that they deal with situations like this every day and are used to discussing personal problems. If you have a partner, it may be helpful for him or her to see the specialist with you so that any fears and worries can be brought out into the open.

5. Seeking Support

Diet

A balanced, nutritious diet will help you to keep as well as possible and cope with the cancer and any side effects of treatment. Depending on the kind of treatment you have had, you may have special dietary needs. A dietician can help to plan the best foods for your particular situation, ones that you find tempting, easy to eat and nutritious. The Resource and Wellness Centre has a resident dietician.

Exercise

You will probably find it helpful to stay active and to exercise regularly if you can. The amount and type of exercise you do will depend upon what you are used to and how well you feel. Discuss with your doctor what is likely to be best for you.

Relaxation techniques

Some people find relaxation or meditation helps them to feel better. The hospital social worker or nurse will know whether the hospital runs any programs, or may be able to advise you on local community programs. The Resource and Wellness Centre offers relaxation and meditation classes.

Caring for someone with cancer

Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. Look after yourself during this time. Give yourself some time out, and share your worries and concerns with someone outside.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take with them another member of the family or a close friend. It also helps to write down questions beforehand, and to take notes during the appointment.

Cancer Information and Support Service

The Resource and Wellness Centre is a service of the National Cancer Society of Malaysia. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specially trained staff. The staff can send you written information and can put you in touch with appropriate services in your own area. Telephone 03 26987300 or email: contact@cancer.org.my.

6. Information Checklist

You may find the following checklist helpful when thinking about the questions you may want to ask your doctor about illness and treatment.

1. What type of cancer do I have?
2. How extensive is my cancer? (How much cancer is there?)
3. What treatment do you advise for my cancer and why?
4. Will my treatment be performed by a doctor who specialises in bladder cancer?

5. Are there other treatment choices for me? If not, why not?
 6. Are there any clinical trials of new treatments that I should know about?
 7. What are the risks and possible side effects of each treatment?
 8. Will I have to stay in hospital, or will I be treated as an outpatient?
 9. How long will the treatment take? How much will it affect what I can do?
How much will it cost?
 10. Will I have a lot of pain with the treatment? What will be done about this?
 11. If I need further treatment, what will it be like and when will it begin?
 12. Will the treatment affect my sexual relationships?
 13. How frequent will my check-ups be and what will they involve?
 14. Are there any problems I should watch out for?
 15. I would like to have a second opinion. Can you refer me to someone else?
 16. Is my cancer hereditary?
- If there are answers you do not understand, feel comfortable to say, 'Can you explain that again?' or 'I am not sure what you mean by...'

Other questions and notes

It can be useful to jot down any other points you may want to discuss with your doctors.

Glossary

Most of the words listed here are used in this web section; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

abdomen

The part of the body between the chest and hips, which contains the stomach, liver, intestines, bladder and kidneys.

adrenal glands

Triangular glands which cover the top of each kidney. The glands produce adrenaline and some other hormones.

anaesthetic

A drug given to stop a person feeling pain. A 'local' anaesthetic numbs part of the body; a 'general' anaesthetic causes temporary loss of consciousness.

angiogenesis

The formation of new blood vessels to support tissue. Angiogenesis enables tumours to develop their own blood supply, which helps them to survive and grow.

BCG

Bacillus Calmette-Guerin, a bacterium responsible for tuberculosis, which is used to treat some bladder cancers.

benign

Not cancerous. Benign cells are not able to spread like cancer cells.

biopsy

The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease.

bladder

The hollow organ that stores urine.

bladder reconstruction

The surgical creation of a new 'bladder' from part of the bowel.

bowel

The part of the digestive system that extends from the stomach to the anus.

carcinoma in situ

Cancer that involves only the cells in which it began and has not spread to deeper layers of the lining.

catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

cautery

Destroying tissue by burning.

cells

The 'building blocks' of the body. A human is made of millions of cells, which are adapted for different- functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

chemotherapy

The use of special (cytotoxic) drugs to treat cancer by killing cancer cells or slowing their growth.

computerised tomography (CT) scan

The technique for constructing pictures from cross sections of the body, by x-raying the part of the body to be examined from many different angles.

cystectomy

The surgical removal of the bladder.

cystitis

Inflammation of the bladder.

cystoscope

An instrument that allows the doctor to see inside the bladder. It also allows removal of tissue samples or small tumours. Cystoscopy is the name for this procedure.

electrosurgery

The use of electrodes, which are devices (like wires) that conduct electricity, to remove diseased tissue, like tumours.

gene

The tiny factors that govern the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. Genes are found in every cell of the body.

haematuria

Blood in the urine.

ileal conduit

A small 'pouch' created from a piece of the bowel to hold urine. It takes the place of the bladder. A stoma allows urine collected in the ileal conduit to flow into a bag.

immune system

A complex network of cells and organs that defends the body against attacks by 'foreign' invaders, like infection. It recognises the difference between normal cells and cancer cells and 'fights' cancer cells.

immunotherapy

The use of treatments which stimulate the body to fight infection and foreign tissue.

incontinence

Loss of bladder control, or urinary leaking.

intravenous

Into a vein.

intravesical chemotherapy

Chemotherapy in a fluid, which is put into the bladder through a tube into the urethra.

invasive bladder cancer

Cancer that has spread beyond the lining of the bladder, into the wall of the bladder. Invasive bladder cancers may also spread beyond the bladder, into other organs.

kidneys

A pair of organs in the abdomen that remove waste from the blood (as urine).

lymph vessels

Part of the lymphatic system. The lymphatic system is part of the immune system, which protects the body against 'invaders', like bacteria and parasites. The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

malignant

Cancerous. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

membrane

A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ.

menopause

The cessation of menstruation.

metastases

Also known as 'secondaries'. Tumours or masses of cells that develop when cancer cells break away from the original (primary) cancer and are carried by the lymphatic and blood systems to other parts of the body. Metastases are named for the organ they came from: for example, bladder cancer, which spreads to the lungs, is bladder cancer, not lung cancer.

partial cystectomy

The surgical removal of part of the bladder.

prosthesis

Artificial substitute for a missing part of the body.

radiation

Energy in the form of waves or particles, including gamma rays, x-rays and ultraviolet rays. This energy can injure or destroy cells by damaging their genetic material. This ability is 'harnessed for good' when it is used in radiotherapy to destroy cancer cells.

radical cystectomy

Surgery for people with bladder cancer. For women, the operation removes the bladder and may also remove the uterus, Fallopian tubes, ovaries, front of the vagina and urethra. In men, it removes the bladder, prostate gland and urethra.

radiotherapy

The use of high-energy radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiotherapy treatment can also harm normal cells, but they are able to repair themselves.

recurrent cancer

A cancer which grows from cells of a primary cancer which evaded treatment. Recurrent cancer may appear up to 20 years after the primary cancer was treated, depending on the type of cancer.

schistosoma

Also called bilharzia. An infection with the tropical parasite, (a flatworm) of the same name. It causes disabling and often fatal disease of the bladder and liver.

stoma

An artificial opening created in the body by surgery.

stomal therapy nurses

Specially-trained nurses who care for and advise people with stomas.

superficial bladder cancer

Cancer that has not spread beyond the lining of the bladder.

tissue

A collection of cells.

transitional cells

Cells lining some organs.

tumour

A new or abnormal growth of tissue on or in the body.

ureter

The tube that carries urine from the kidney to the bladder.

urethra

The tube through which urine leaves the body. It empties urine from the bladder.

urine

Fluid containing water and waste products. Urine is made by the kidneys, stored in the bladder, and leaves the body through the urethra.

urologist

A doctor who specialises in diseases of the urinary organs in females and the urinary and sex organs in males.

urostomy

An operation to create an opening from inside the body to the outside, making a new way to pass urine.

urothelium

The membrane lining the bladder.

uterus

The part of the female reproductive tract that allows an embryo to become implanted in the inner wall and to nourish a growing foetus.