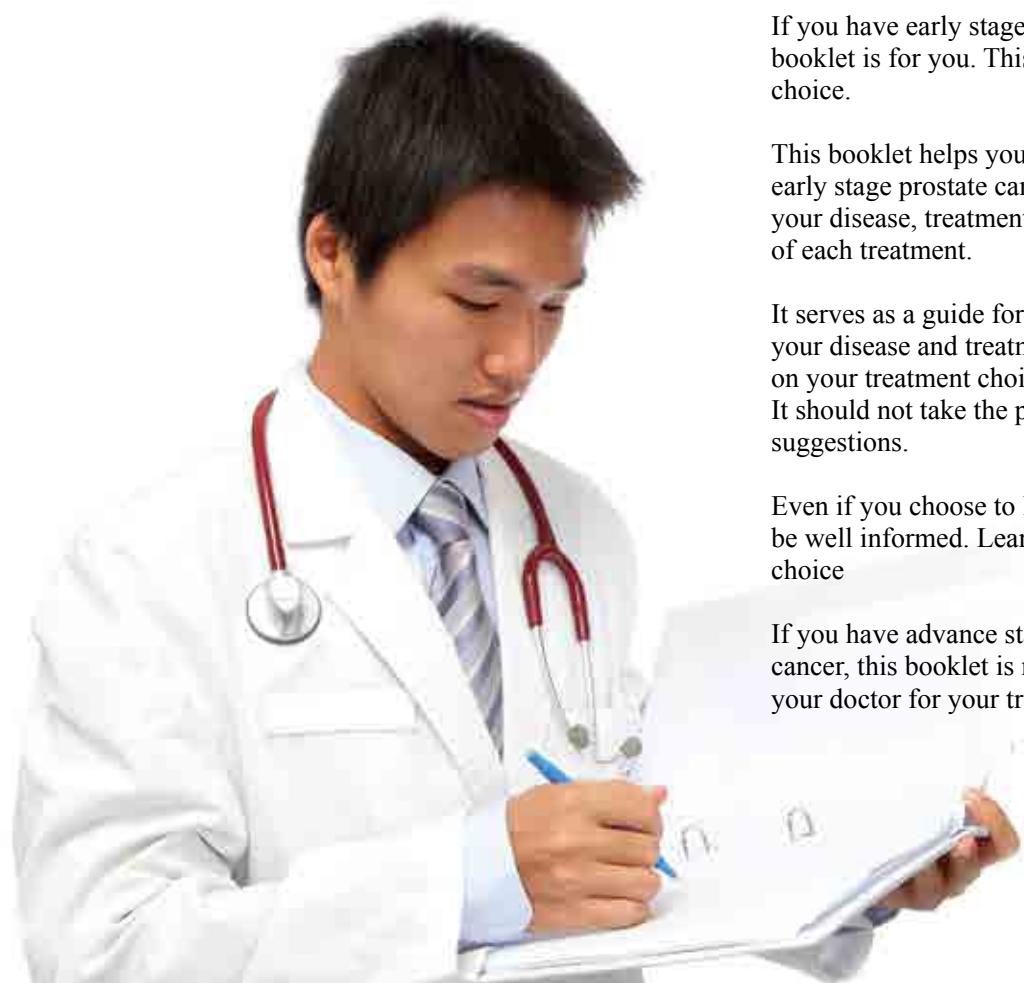


MAKING THE CHOICE

Deciding What to Do about Early Stage Prostate Cancer

HOW THIS BOOKLET HELPS



If you have early stage prostate cancer (Stage I and II), this booklet is for you. This booklet will help you make your choice.

This booklet helps you to understand medical facts about early stage prostate cancer. It provides you the facts about your disease, treatment choices and the benefits and risks of each treatment.

It serves as a guide for you to have better understanding of your disease and treatment choices, so that you can decide on your treatment choice after discussing with your doctor. It should not take the place of your doctor's advice and suggestions.

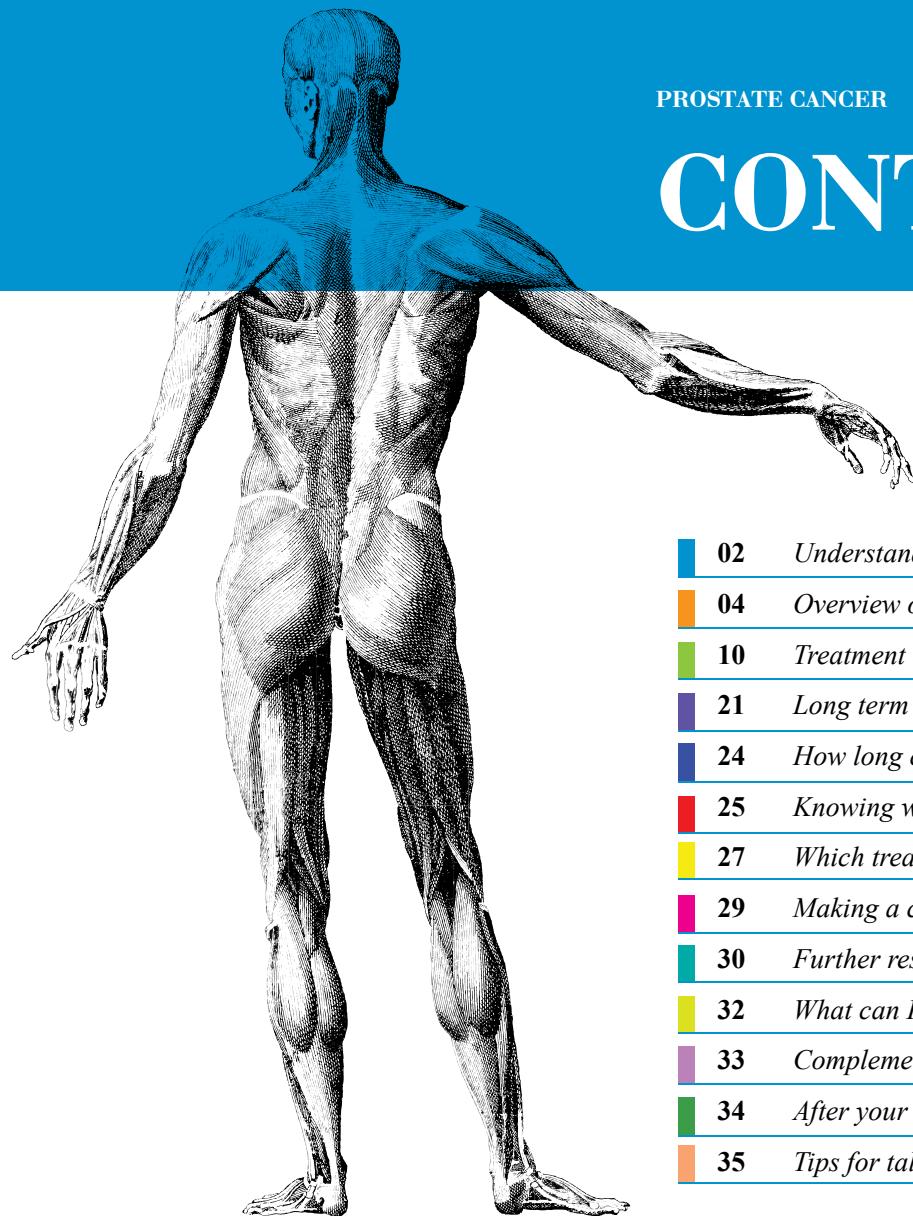
Even if you choose to let the doctor decide, you need to be well informed. Learn all you can so you can make your choice

If you have advance stage (Stage III and IV) prostate cancer, this booklet is not suitable for you. Discuss with your doctor for your treatment options.

THESE ARE SOME OF THE COMMON COMMENTS FROM PATIENTS WHO HAVE EARLY PROSTATE CANCER.

- “When I was told that I have prostate cancer, I was not told about all the available treatment choices like watchful waiting and radiotherapy. I only knew about surgery.”
- “After I was diagnosed, the first thing that crossed my mind was that I’m going to die. I was preparing for death and withdrew myself from all the social activity that I used to be very actively involved in.”
- “When my doctor asked me if there are any questions I would want to clarify, actually sometimes we don’t know what to ask,because in order to ask, you must know what you want to know.”
- “When my doctor told me I had prostate cancer, I was shocked. I mean it’s quite traumatic because we always think cancer is a death sentence. Okay, that’s it, you’re going to die very soon.”





PROSTATE CANCER

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- 02** *Understanding your prostate and its functions*
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UNDERSTANDING YOUR PROSTATE AND ITS FUNCTIONS

The prostate is part of the male reproductive system. It is below the bladder and in front of the rectum in the pelvic region. (Refer picture below). The prostate is about the size of a chestnut (buah berangan) when it is healthy. It surrounds the tube called the urethra that carries urine and semen out of the penis.

Prostate is a gland that helps make semen which is released during ejaculation. The prostate produces another substance called PSA (prostate specific antigen). PSA level can be higher than normal in men with prostate cancer as well as in some other benign prostate conditions such as BPH/benign prostatic hyperplasia (prostate enlargement) or prostatitis (infection of the prostate).

WHAT CAN HAPPEN TO THE PROSTATE

Benign Prostatic Hyperplasia or BPH:

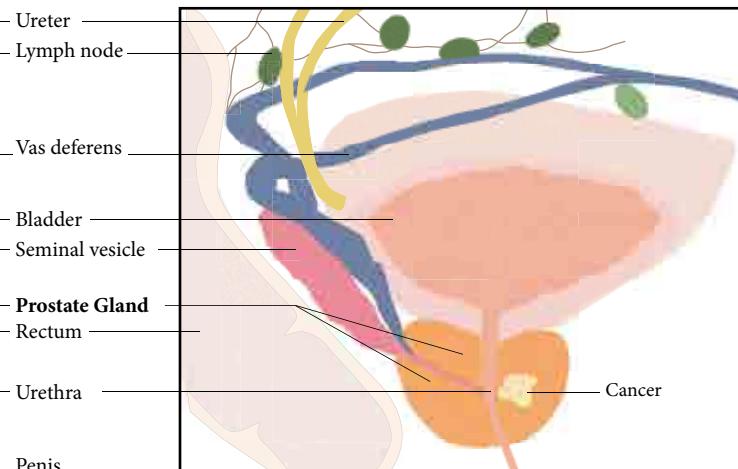
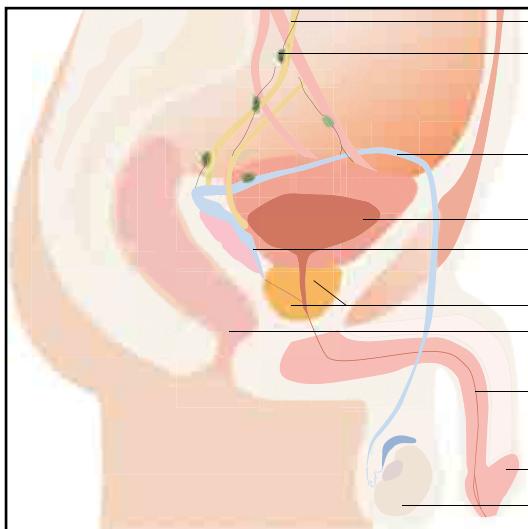
As you get older, the prostate can grow. If the prostate becomes too large, it can press on the urethra (tube that carries urine and semen out of the penis). This may cause difficulty in urination.

Prostatitis:

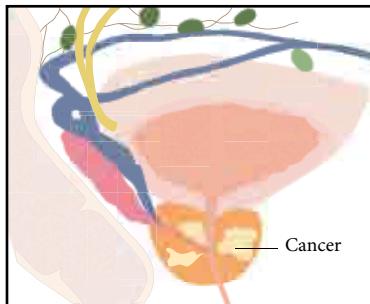
The prostate becomes inflamed. It happens when there is an infection in the area of prostate.

Prostate Cancer:

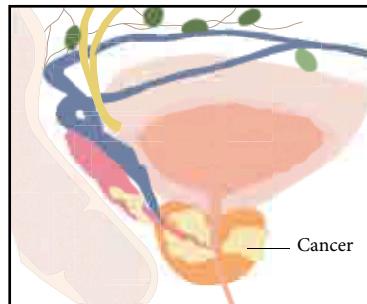
The prostate can also develop cancer. The cancer is localized when it is in the early stage (stage 1 and 2). It can spread to the nearby tissue such as the seminal vesicles, or later get into the bloodstream and lymphatic system and spread to other parts of the body such as bones and lymph nodes (stage 3 and stage 4 cancer). The pictures below illustrate the stages of prostate cancer.

Understanding your prostate and its functions

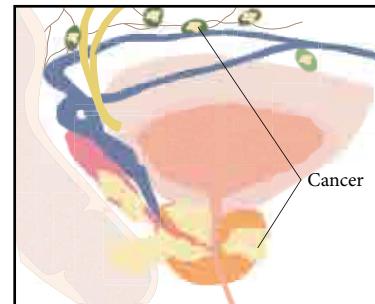
Stage 1: cancer is found in one-half or less of one lobe of the prostate



Stage 2: cancer is found in more than one-half of one lobe of the prostate.



Stage 3: cancer has spread beyond the outer layer of the prostate and may have spread to the seminal vesicles.



Stage 4: cancer has spread beyond the seminal vesicles to nearby tissue or organs, such as the rectum, bladder, or pelvic wall or spread to other parts of the body such as bones and lymph nodes

OVERVIEW OF PROSTATE CANCER

HOW IS PROSTATE CANCER DIFFERENT FROM OTHER CANCER?

A photograph of a man from the waist up, wearing a white button-down shirt and a pink and black striped tie. He has his hands clasped in front of him at his waist. The background is plain white.

Prostate cancer is a very different kind of cancer. Most prostate cancers grow very slowly and do not cause problems especially for those with early stage prostate cancer. Thus, you can take your time to decide on your treatment choices. There is no hurry to start the treatment immediately.

Most men with prostate cancer do not die from prostate cancer. Because it is slow growing, men often die from other conditions such as heart attack. However, a few prostate cancers grow more quickly and there is a chance it could grow and spread and even cause death.

Overview of Prostate cancer

Medical tests

Your doctor will take into account of your general health, the results of your tests and examinations, and the Gleason score (a method to grade prostate cancer) of your cancer when talking with you about your treatment choices.

What are the common tests done for you?

- PSA test

The PSA is a blood test.

The lower the PSA, the better the chances are that treatment (observation, surgery, or radiation) will be successful.

- Grading of the cancer (Gleason score)

This is categorised based on various samples taken from prostate biopsy and examined under a microscope. This score tells how different the prostate cancer tissue looks from normal prostate tissue and how likely it is that the cancer will grow or spread.

- Staging of the tumour

The tests include digital rectal examination, bone scan, MRI or CT scan.

The lower the stage, the better the chance of a successful treatment.

Overview of Prostate cancer



WHO ARE THE DOCTORS WHO MANAGE PROSTATE CANCER?

The doctors involved in managing your cancer are mainly the urologists and oncologists.

Urologists are doctors who treat diseases of the urinary system and male sex organs. They are the surgeons who take the biopsy from you and they are usually the first doctors who tell you about your disease. They carry out surgery to remove the cancer.

Oncologists are doctors who specialize in treating cancer using chemotherapy, hormone therapy and radiation. They are the doctors who are going to manage your radiation therapy if you choose this treatment. You need to see the oncologist for further understanding of the radiation procedures and its side effect. They will arrange the follow up with you if you choose radiation as your treatment.

WHAT ARE THE TREATMENT CHOICES FOR EARLY STAGE PROSTATE CANCER?

There are 3 standard treatments for early stage prostate cancer: observation, surgery, and radiation.

Observation

Your doctor will monitor the progress of your prostate cancer regularly through follow-ups. There is no surgery or radiation treatment given. Thus, you avoid the side effects from those treatments if you choose this option.

There are two types of observation:

- Watchful waiting: This is appropriate if you and your doctor decide to only treat the cancer when it causes symptoms.
- Active surveillance: You and your doctor will monitor the prostate cancer closely by using laboratory tests. When there is a sign of cancer growing (shown by the laboratory tests), you can choose another type of treatment.

Surgery and radiotherapy are two other treatment choices. They may cure you, but they may also cause side effects, such as problems with controlling your bladder and bowel as well as affecting your sexual function (problem with erection).

Overview of Prostate cancer

Prostate cancer risk group

Early prostate cancer can be classified into a low-, medium-, or high-risk group based on PSA level, stage and grade (Gleason score) of prostate cancer. The risk refers to the chance of the cancer growing or spreading over time.

- Low-risk prostate cancer is not likely to grow or spread for many years.
- Intermediate-risk prostate cancer is not likely to grow or spread for a few years.
- High-risk prostate cancer may grow or spread within a few years.

If you are in low or intermediate-risk group, you can have the options of choosing observation (watchful waiting or active surveillance), surgery or radiotherapy. If you are in the high risk groups, the doctor would recommend that you choose either surgery or radiation because there is a higher risk for progression of the prostate cancer.

Doctors classify low-, medium-, and high-risk groups as follows:

| | PSA level* | Gleason score | Tumour stage [#] |
|-------------------|--------------------|---------------|---------------------------|
| Low-risk | Less than 10 ng/ml | 6 or lower | T1(a to c) or T2a |
| Intermediate-risk | 10-20 ng/ml | 7 | T2b |
| High-risk | More than 20 ng/ml | 8 or higher | T2c |

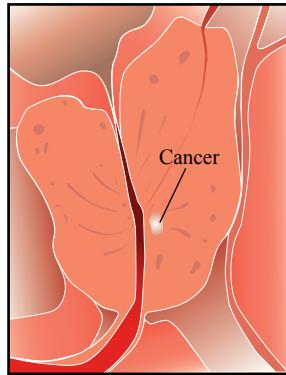
* PSA prostate specific antigen

tumour stage is illustrated in Figure 1. T1: cancer cannot be felt during digital rectal examination (DRE), T2: cancer can be felt during DRE

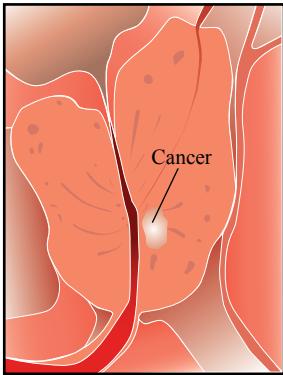
HOW DOES YOUR DOCTOR CLASSIFY YOUR RISK GROUP

Overview of Prostate cancer

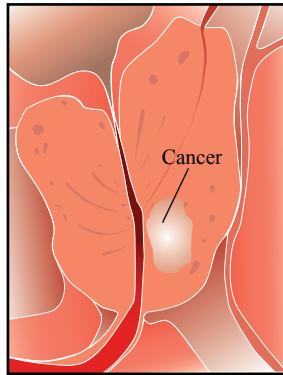
Figure 1: Staging of prostate cancer



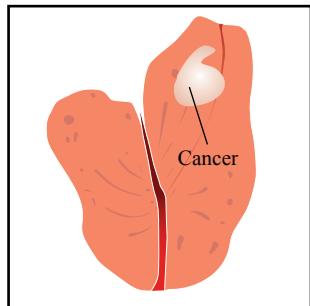
Stage T1a



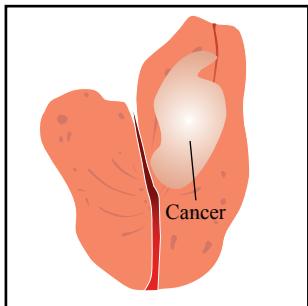
Stage T1b



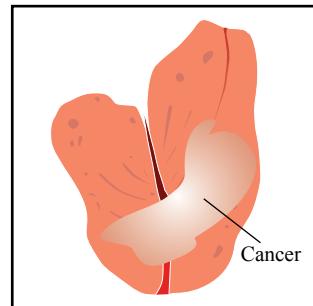
Stage T1c



T2a



T2b



T2c

TREATMENT CHOICES

OBSERVATION (ACTIVE SURVEILLANCE/ WATCHFUL WAITING)

WHAT DO I NEED TO KNOW ABOUT OBSERVATION?

Observation can be used for men with early-stage prostate cancer because the cancer often grows so slowly that it may not cause problem during a man's lifetime.

Active surveillance:

- Involves regular follow up with examinations and tests.
- PSA and prostate examination will be done every few months and prostate biopsy every 1 to 3 years. The options of active treatment such as surgery or radiation remain an option in case of disease progression.
- May be right for you if you have a small cancer confined to the prostate gland and it does not appear to be spreading or growing fast.

Watchful waiting:

- Involves less frequent follow up and examinations than active surveillance.
- These are only done if there is concern that the cancer is growing too fast or you develop symptom.
- May be right for you if you are older or have a lot of serious health problems. And you may not live long enough for the cancer to cause any problems.

The cost for this option is mainly for consultation and testing. The cost will depend on the hospital you are seeking treatment from.

WHAT ARE THE ADVANTAGES OF OBSERVATION?

- You can avoid the complications of active treatment (surgery or radiotherapy) like:
 - trouble controlling bladder or bowels.
 - trouble having an erection.
- You can always change your mind and begin other treatments later.
- It is cheaper compared to surgery or radiotherapy. Active surveillance is more costly than watchful waiting as it requires more frequent testing and follow up.

WHAT ARE THE DISADVANTAGES OF OBSERVATION?

- You may feel worried or anxious about living with cancer and putting off the treatment.
- The cancer needs to be followed closely.
- You need to go for blood tests and biopsies more frequently (in the case of active surveillance).
- The cancer may spread and become harder to treat. However, the chance is low if the prostate cancer risk of progression is low.



SURGERY

WHAT DO I NEED TO KNOW ABOUT SURGERY?

- Surgery is a treatment choice for men with early-stage prostate cancer who are in good health.
- You will be admitted to the hospital for one or more days.
- The entire prostate gland with the cancer in it will be removed during surgery.
- Sometimes, the doctor will also remove the lymph glands (nodes) next to the prostate.
- The surgery usually takes about 2 to 4 hours.
- The surgery can be performed in several ways:

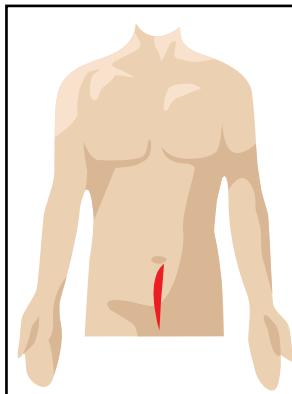
Treatment choices

Open prostatectomy

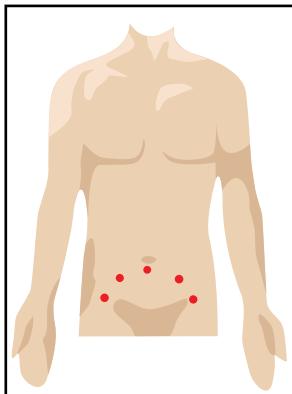
- In this surgery, the prostate is removed through a single long cut made in the abdomen from a point below your belly button to just above the pubic bone.

Laparoscopic / robotic surgery

- In this type of surgery, a laparoscope is used to remove the prostate.
- A laparoscope is a long slender tube with a light and camera on the end.
- This surgery is done through 4 to 6 small cuts in the belly button and the abdomen, instead of a single long cut in the abdomen (key hole surgery).
- A robot can be used to assist this type of surgery.



Open prostatectomy incision



Robotic prostatectomy incision

- Laparoscopic and robotic surgery may cause less pain, bleeding and require shorter hospital stay.
- The results of the surgery such as cancer control and long term complications are the same for either open or laparoscopic/robotic surgery.
- As long as your surgeon is experienced, the type of surgery (open or laparoscopic/robot) usually doesn't matter.
- In some cases, the surgeon can do a "nerve-sparing" surgery. This can lower the chance of complications such as urinary incontinence or erection problem.
- But for some men, "nerve-sparing surgery" cannot be done. This happens when the nerve is too close to the cancer and the surgeon might have to remove the nerve to lower the chance of leaving the cancer behind.
- After the surgery, a tube (catheter) will be left in your bladder to drain your urine. It will be there for 1 to 2 weeks to help the wound heal.
- The cost for open prostatectomy ranges from RM500-2,000 (in government hospitals) to RM20,000-25,000 (in private hospital)
- After the surgery, you are advised to rest and avoid strenuous activities for 4-6 weeks before resuming your usual routine activities.
- You are advised to have a healthy diet and do appropriate physical activities. There is no special food restriction.

Treatment choices

WHAT ARE THE ADVANTAGES OF SURGERY?

- Surgery can offer a cure if the cancer is removed completely.

WHAT ARE THE DISADVANTAGES OF SURGERY?

1. Sometimes not all cancer cells are removed

- Sometimes men may need additional treatment, such as radiation, to get rid of the remaining cancer cells so as to improve the chance of cure.

2. Complications of the surgery

- **Bleeding:** You may have bleeding that requires a blood transfusion.
- **Blood clots:** You can have blood clots in the legs or lungs.
- **Infection:** You can have a wound infection at the site where surgery was performed, or in the urine.

Problems of controlling your urine (also known as incontinence)

- You may not be able to control your urine after the surgery.
- Your urine may leak when you cough, sneeze, or strain (e.g. when you lift something), or change position suddenly.
- Leaking of urine may last from a few weeks to several months or longer.
- In most cases, the leaking stops on its own without the need for special treatment.

RADIOTHERAPY

WHAT DO I NEED TO KNOW ABOUT RADIOTHERAPY?

Radiotherapy works by using high-energy x-rays to destroy cancer cells in the prostate gland. It can be given from either outside (external beam radiotherapy) or inside (brachytherapy - internal radiotherapy) the body. In Malaysia, radiotherapy for prostate cancer is usually given as external beam radiotherapy.

If you choose to have radiotherapy as a treatment, your doctor may suggest hormone therapy to achieve better long term outcome or to reduce the prostate size before radiotherapy. Your doctor will discuss this treatment option with you.

1. External beam radiotherapy (EBRT)

- EBRT is given from outside the body and is directed specifically at the prostate gland. It is given in the hospital radiotherapy department, usually as daily sessions Monday to Friday, with a rest at the weekend. Each session takes about 10-20 minutes depending on the technique used. The treatment is given as outpatient and so there is no need for an admission. For early prostate cancer, the course of treatment may last from 4

to 8 weeks. The treatment is planned and given by a team consists of the oncologist, medical physicist and therapy radiographer.

- Before starting the course of radiotherapy, you need to undergo a planning session called simulation. The aim of simulation is to ensure that radiation is targeted at the area to be treated to increase the chance of cure while sparing the normal tissues as much as possible to reduce side effects. The treatment is planned by the radiotherapy team using a computer planning system.
- Simulation may involve one or two visits to the hospital. The session usually lasts about 20-30 minutes. During this session, CT scan images of the pelvis are taken. Small pinpoint ink may be marked on your skin during simulation. These marks help the radiographer to position you during each treatment so that the radiation can be delivered accurately to the area being treated. The radiographers will give you the date to start treatment after this session.

Treatment choices

- At the beginning of each EBRT session, the radiographer will position you on the couch. Once the position is set, you will be asked to lie still for a few minutes for the treatment. During the treatment, you will be left alone in the room but you will be able to communicate with the radiographers who are in another room.
- EBRT can be delivered in several ways. The aims are to improve the control of cancer and lower the chance of long term side effects. The techniques are listed below :
 - Conformal radiotherapy (CRT)
 - Intensity modulated radiation treatment (IMRT)
 - Image guided radiation treatment (IGRT)
 - Stereotactic radiotherapy (SRT)
- Your oncologist will discuss the suitable technique with you.

2. Brachytherapy

- Brachytherapy is an internal radiotherapy which involves putting a solid radioactive source close to, or placed into, the tumour.
- Like EBRT, brachytherapy is directed specifically at the prostate gland but is given from inside the gland itself. This technique destroys cancer cells from within the tumour without causing too much damage to the normal tissue around the prostate.

- Brachytherapy is not widely available. It may not be suitable for you if you already have surgery to the prostate gland (transurethral resection of the prostate, TURP), urinary symptoms or large prostate size. Brachytherapy has not been used as long as external beam radiation. So the chances of cure and side effects are not as well known.
- You will need to undergo an ultrasound to guide the insertion of the radioactive seeds or applicator needles. This procedure is done in the operating room under general anaesthesia. However, you might be able to go home on the same day.

How much does it cost?

- The cost of treatment varies according to the type and technique of radiotherapy used and the treatment locations (government versus private centres).
- The cost of standard radiotherapy range from RM500 – RM5000 in government hospitals and up to RM 15,000 in private hospitals.
- However the cost for other more complex radiotherapy techniques are higher depending on the type and setting.

Treatment choices

WHAT ARE THE ADVANTAGES OF RADIOTHERAPY?

- If radiotherapy can kill all cancer cells, a man with prostate cancer can be free from the disease for the rest of his life.
- ED is less likely to happen with radiotherapy compared to surgery, but more likely than with observation.
- Radiotherapy has fewer problems with urine leaking compared to surgery.
- You do not need to be admitted to the hospital, unlike surgery.

WHAT ARE THE DISADVANTAGES OF RADIOTHERAPY?

- Radiation may not kill all cancer cells.
- Out of 100 men who choose this treatment options, 2 to 31 men will have the risk of dying from prostate cancer whereas 69 to 98 may survive. 
- If radiotherapy does not cure your cancer, surgery may be necessary. However, surgery may be more difficult because of scarring around the prostate after radiotherapy.
- You will be seen by your oncologists regularly during radiotherapy to monitor for and treat side effects. The side effects that can occur during treatment include:
 - Tiredness
 - Mild skin redness and dryness
 - Urinary symptoms: frequency (passing urine frequently) (34 in 100 men may have this and 66 may not), urgency (urine leakage when

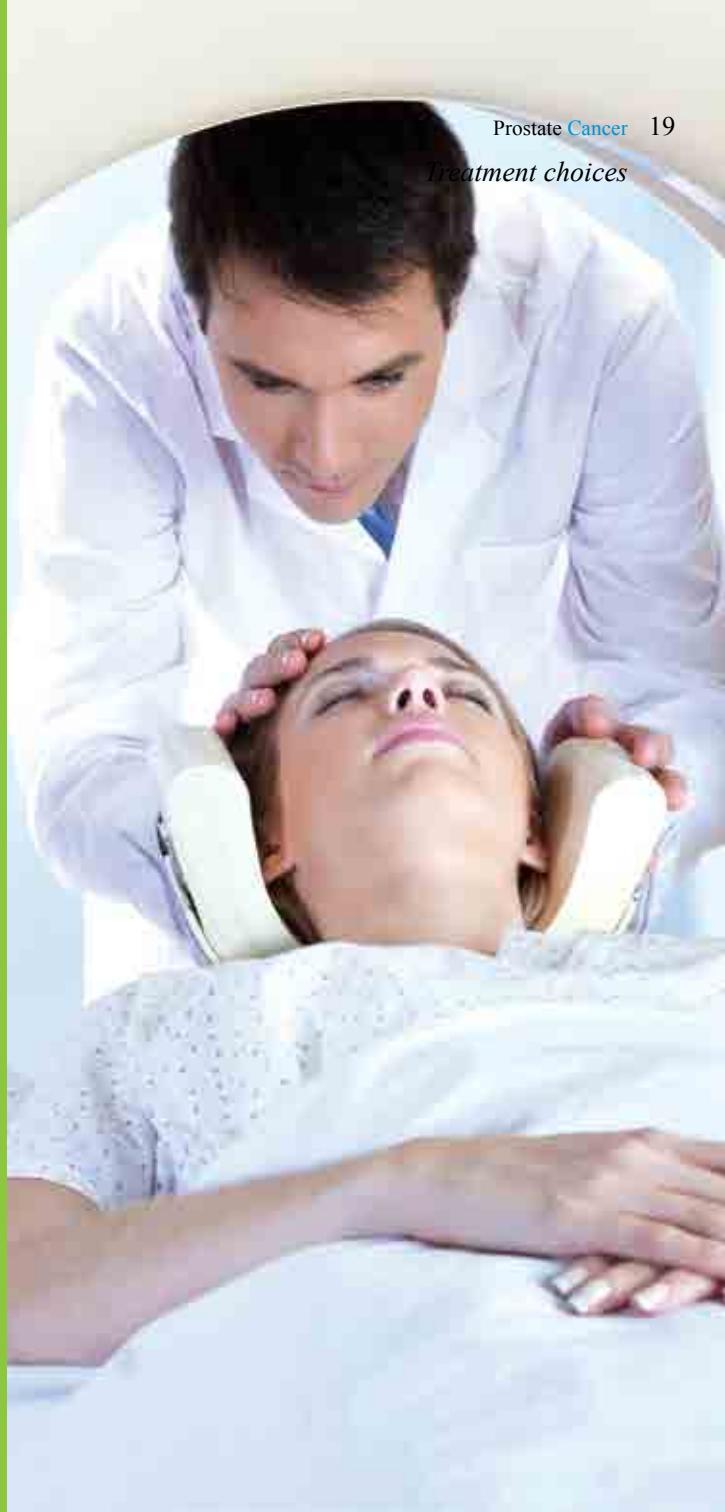
Treatment choices

feeling of urinate), weak stream (23 in 100 men may have this and 77 may not), painful urination (12 in 100 men may have this and 88 may not), blood in the urine (less than 1 in 100 men may have this and more than 99 may not), leaking of urine (6 in 100 men may have this and 94 may not).

- Bowel symptoms: diarrhoea (16 in 100 men may have this and 84 may not), urgency (18 in 100 men may have this and 82 may not), painful passing motion (7 in 100 men may have this and 93 may not), blood in stool (3 in 100 men may have this and 97 may not).
- Discomfort in the abdomen (rare)
- These side effects usually occur two weeks after starting EBRT. They are usually manageable and improve gradually after completion of radiotherapy.
- However, there are risk of permanent side effects as listed below :

Problems controlling your urine (leaking of urine):

- You may have difficulty controlling your urine (leaking of urine) for a few weeks.
- For EBRT, out of 100 men with early prostate cancer, 7 may have persistent leaking of urine and 93 may not.
- For brachytherapy, out of 100 men with early prostate cancer, 10 may have persistent leaking of urine and 90 may not.



Treatment choices

Problems passing urine:

- You may find it painful or difficult to pass urine after radiotherapy. Painful urination may be due to a prostate or urinary tract infection. You may also pass urine more often.
- For EBRT, out of 100 men with early prostate cancer, 11 may have persistent problem of passing urine and 89 may not.
- For brachytherapy, out of 100 men with early prostate cancer, 16 may have persistent problem of passing urine and 84 may not.

Change in bowel habit (diarrhoea, pain, or bleeding from the rectum)

- For EBRT, out of 100 men with early prostate cancer, 11 may have bowel symptoms and 89 may not.
- For brachytherapy, out of 100 men with early prostate cancer, 8 may have bowel symptoms and 92 may not.

Erection problem:

- As with surgery, you may have problem having and keeping an erection after radiotherapy. This may affect your feelings about sex and about yourself. However, it is possible to have sexual pleasure even without an erection or an ejaculation (dry orgasm).
- For both types of radiotherapy, about 35 to 45 men out of 100 may have problem with erection.

- ED can be treated with:
 - Oral Tablets.
 - Vacuum device.
 - Injections.
 - Penile implant.

Risk of bladder and rectal cancer:

- Radiation is a risk factor of cancer and this may occur in organs which are exposed to radiation during treatment e.g. bladder or rectum.
- The risk of bladder or rectal cancer is less than 1 man out of every 100 patients treated with radiotherapy (or 160 of every 100,000).

Cryotherapy

- It is also called cryoablation or cryosurgical ablation.
- It involves freezing the prostate to destroy cancer cells.
- In this type of treatment, the doctor delivers liquid nitrogen to the prostate through a special probe. The doctor inserts the probe into the prostate through an incision between the scrotum and anus. Sometimes, the doctor may also use needles to deliver liquid nitrogen to the prostate without making an incision.
- Cryotherapy is still considered experimental in the treatment of early prostate cancer and is not a standard practice.

LONG TERM SIDE EFFECTS OF TREATMENT CHOICES

The numbers used in the table below come from published articles. Your doctor will discuss your risk of developing these side effects based on individual assessment.

| | Observation | | Active Treatment | | |
|--|--|--|---|--|---|
| | Watchful Waiting | Active Surveillance | Surgery | External “beam radiotherapy” | Internal “seed radiotherapy” |
| Problem with erection (ED): At 2 year | 45 in 100 may have ED, 55 may not | 45 in 100 may have ED, 55 may not | 58 in 100 may have ED, 42 may not | 60 in 100 may have ED, 40 may not | 51 in 100 may have ED, 49 may not |
| | - | - | 87 in 100 may have ED, 13 may not | 93 in 100 may have ED, 7 may not | - |
| Problems holding urine or leaking (Incontinence): At 2 year | 6 in 100 may have incontinence, 94 may not | 6 in 100 may have incontinence, 94 may not | 14 in 100 may have incontinence, 86 may not | 7 in 100 may have incontinence, 93 may not | 10 in 100 may have incontinence, 90 may not |
| | - | - | 18 in 100 may have incontinence, 82 may not | 9 in 100 may have incontinence, 91 may not | - |

Long term side effects of treatment choices

| | Observation | | Active Treatment | | |
|--|------------------|---------------------|--|---|---|
| | Watchful Waiting | Active Surveillance | Surgery | External “beam radiotherapy” | Internal “seed radiotherapy” |
| Passing urine (At 2 year): Painful | - | - | <1 in 100 may have painful passing urine, 99 may not | 1 in 100 may have painful passing urine, 99 may not | 5 in 100 may have painful passing urine, 95 may not |
| Frequency | - | - | 10 in 100 may have frequency, 90 may not | 14 in 100 may have frequency, 86 may not | 20 in 100 may have frequency, 80 may not |
| Loose bowels (Diarrhoea): At 2 year | - | - | <1 in 100 may have diarrhea, 99 may not | 10 in 100 may have diarrhea, 90 may not | 7 in 100 may have diarrhea, 93 may not |
| At 15 year | - | - | 5 in 100 may have diarrhea, 95 may not | 16 in 100 may have diarrhea, 84 may not | - |

Long term side effects of treatment choices

| | Observation | | Active Treatment | | |
|---|------------------------------------|---|--|---------------------------------------|-------------------------------|
| | Watchful Waiting | Active Surveillance | Surgery | External “beam radiotherapy” | Internal “seed radiotherapy” |
| Risk of dying from treatment (Death) | Not applicable | Not applicable | Rare (0-2 in 100 may die, 98 -100 may not) | Rare (2 in 1000 may die, 998 may not) | Rare* (no data) |
| Risk of dying from prostate cancer in 10 years | | | | | |
| Low risk | 3-11 in 100 may die, 89-97 may not | 3 in 100 may die, 97 may not(7 years follow up) | <1-7 in 100 may die, 93-100 may not | 2 in 100 may die, 98 may not | 4 in 100 may die, 96 may not |
| Intermediate risk | 11 in 100 may die, 89 may not | - | 3- 5 in 100 may die, 95-97 may not | 4 in 100 may die, 96 may not | 13 in 100 may die, 87 may not |
| High risk | 18 in 100 may die, 82 may not | - | 8- 9 in 100 may die, 91-92 may not | 8 in 100 may die, 92 may not | 31 in 100 may die, 69 may not |

* Rare means less than 1 in 100.

** Active surveillance is so new we don't know the number to put in this table yet.

HOW LONG I CAN EXPECT TO LIVE AFTER TREATMENT?

- Most men with early-stage prostate cancer can expect to have many healthy years ahead of them. The average age for men to be diagnosed to have early-stage prostate cancer is 65 years.
- With the diagnosis of early prostate cancer, the chances of surviving in the long term are quite similar with any treatment option. This is because in some men, the prostate cancer may not cause problem in their lifetime, such that they die due to other causes, such as heart attack or stroke, rather than from prostate cancer.
- At 10 years after diagnosis, out of 100 men, 50-70 men will still be alive.



KNOWING WHAT IS IMPORTANT TO YOU

When discussing options with your doctor, it is important to think about what is personally important to you. One helpful way is to think about your decision in terms of:

- Your treatment goals (something you want to achieve through your choice of treatment)
- Your treatment concerns (worries or questions you may have)

Treatment goals

How important are the following to you when making a decision about prostate cancer treatment? (Tick your priority level on each item on the scale below).



| | Not Very Important | Important | Very Important |
|---|--------------------------|--------------------------|--------------------------|
| • Chance of survival | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Curing the cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Curing any symptoms I may have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Having the best possible sexual performance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Having good bowel and bladder control | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Cost of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Other _____ | | | |

Knowing what is important to you

Concerns

What are your concerns about prostate cancer treatment?

(Tick your concerns) you can tick more than one box

I don't have enough information to make a choice. I want to know more about

- I am concerned about the treatment cost.
- I want to know about how treatment will affect my lifestyle.
- I want to know about how treatment will affect my work.
- I have religious concerns about the treatment.
- I want to know more about survival.
- I want to know more about the experiences of other people with prostate cancer.
- I want to know more about diet during treatment.
- I need more support in making a decision. I want more:
 - family support
 - financial support
 - spiritual support
 - support from doctors
 - peers/ support group
- I am distressed (e.g. shocked, confused, angry, panicked)

WHICH TREATMENT IS A GOOD CHOICE FOR ME?

Now that you have understood the treatment options available, the advantages and disadvantages of each option, and considered what is important to you, you may want to consider the following factors before making a decision.



Which treatment is a good choice for me?

| Treatments Options | Things to Consider |
|---|--|
| Watchful waiting or Active surveillance | <ul style="list-style-type: none"> • If your cancer is: <ul style="list-style-type: none"> - low-risk (see page 10) - smaller or a slow-growing type of prostate cancer - in the prostate only • If you are in your 70s or older, or have serious medical problems. • If you are able to accept the fact that the cancer will remain in your body. • If you are able to go for check-ups and undergo tests regularly |
| Surgery | <ul style="list-style-type: none"> • If you are younger than 70 and in good health. • If you want the cancer to be removed. • If you are able to accept that you might have side effects from surgery. • If you are able to accept that you may still need radiotherapy after your surgery. |
| Radiotherapy | <ul style="list-style-type: none"> • If you are a man of any age with early-stage prostate cancer. • If you have serious health problems that do not allow you to have surgery. • If you are able to go for treatment 5 days a week for up to 9 weeks. • If you have high-risk cancer (see page 16) that is less likely to be cured by surgery alone. |

MAKING A CHOICE

Are you ready to make a choice?



Yes, I am ready

No, I am not ready.

If yes, what is your choice
(tick one):

- Watchful waiting
- Active surveillance
- Surgery
- External beam radiation
- Internal seed radiation (brachytherapy)

FURTHER RESOURCES

(LOCAL AND INTERNATIONAL RESOURCES)

| Name | Description | Contact Number/Website |
|--|--|---|
| Patient Support Group- National Cancer Society of Malaysia | A patient support group organised by the National Cancer Society. Prostate cancer patients and survivors meet up once in 2 months. | http://cancer.org.my/find-support/support-group-programs/ |
| Prostate Cancer- Malaysian Oncological Society | English language website on prostate cancer. A Chinese version pdf is also available. | http://www.malaysiaoncology.org/article.php?aid=32 |
| Kanser Prostat- Ministry of Health MyHealth portal | Malay language website on prostate cancer. | http://www.myhealth.gov.my/v2/index.php/my/kanser-prostat |
| Making the Choice: Deciding what to do about early stage Prostate Cancer | Michigan Cancer Consortium's website on facts about your disease, your treatment choices, and the possible results of those choices. | http://www.prostatecancerdecision.org/ |
| NHS Choices: Prostate Cancer | A patient website by the NHS UK on the symptoms, causes, diagnosis, treatment and living with prostate cancer. | http://www.nhs.uk/conditions/Cancer-of-the-prostate/Pages/Introduction.aspx |
| Treating Prostate Cancer: A Guide for Men With Localized Prostate Cancer | A patient decision aid from the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. | http://effectivehealthcare.ahrq.gov/ehc/products/9/98/ProstateCancerConsumer.pdf |
| Malaysia Urological Association (MUA) | Urology diseases | http://www.muacme.org/section.php?sid=28&pb=Normal |

Further resources (local and international resources)

Malaysia Hospitals with radiotherapy service

| Hospitals |
|---|
| Goverment Hospitals |
| Hospital Kuala Lumpur, Kuala Lumpur |
| Institut Kanser Negara, Putrajaya |
| Penang General Hospital# |
| Melaka General Hospital# |
| Hospital Sultan Ismail, Johor Bharu |
| Hospital Wanita & Kanak-Kanak Sabah, Likas |
| Hospital Umum Sarawak, Kuching |
| University Malaya Medical Centre, Kuala Lumpur |
| University Kebangsaan Malaysia Medical Centre, Cheras |
| Hospital Universiti Sains Malaysia, Kubang Kerian |

| Private Hospitals |
|--|
| Sime Darby Medical Centre, Subang Jaya |
| Pantai Hospital Kuala Lumpur |
| Damansara Specialist Hospital, Petaling Jaya |
| Beacon Hospital, Petaling Jaya |
| Gleneagles Hospital, Kuala Lumpur |
| Prince Court Medical Centre, Kuala Lumpur |
| Tung Shin Hospital, Kuala Lumpur |
| Sri Kota Specialist Medical Centre, Klang |
| Ipoh Specialist Centre, Ipoh |

| |
|--|
| Fatimah Hospital, Ipoh |
| Mount Miriam Cancer Hospital, Penang |
| Pantai Hospital, Penang |
| Loh Guan Lye Specialist Centre, Penang |
| Gleneagles Penang, Penang |
| Mahkota Medical Centre, Melaka |
| Pantai Hospital, Ayer Keroh, Melaka |
| Nilai Cancer Institute, Nilai |
| KPJ Johor Specialist Hospital, Johor Bharu |

WHAT CAN I EAT

Besides making a decision about treatment options, some patients are also concerned about what kind of diet to eat. For example, if they should take certain types of food, supplements or vitamins.

In general, doctors recommend that patients with prostate cancer should maintain a healthy lifestyle by taking a balanced diet and exercising regularly. There is little evidence to show that specific types of food can affect cancer prevention or progression



COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

Complementary and alternative therapies for prostate cancer are common in Malaysia. Some examples are herbs (such as snake grass, certain types of mushrooms, or ayurvedic herbs), supplements (such as lycopene) and mind-body medicine (such as meditation and medical Qi Gong). However, there is little evidence on whether CAM therapies can treat your cancer. If you plan to or are using CAM, you should inform your doctor so that he or she will be aware of your CAM treatment regime and advise you accordingly.



AFTER YOUR TREATMENT IS OVER



Getting support

After your treatment is over, many men will feel relieved, but some may also feel sad especially if they experience side effects. This is a stressful time. If these feelings are difficult for you, there are many ways to get help, including talking with your doctor, reading books, talking openly to family and friends, and going to a prostate cancer support group (refer to ‘Further resources’ on page 30).

Following up visits with your doctor

You will need to have regular follow-up with your doctor because prostate cancer can relapse, even after treatment. The visits will involve:

- A digital rectal examination
- A PSA test

The doctor will continue to monitor your PSA level because an increase in your PSA level can be an early warning that your cancer is recurring.

Your cancer is in remission if all your tests are normal. However, you should still visit your doctor regularly and undergo tests from time to time.

Living a healthy lifestyle

In general, doctors recommend that patients with prostate cancer should maintain a healthy lifestyle by eating a balanced and nutritious diet and exercising regularly.

If the cancer returns

You should be aware that no treatment is foolproof. In general, a cancer that comes back is harder to treat the second time around. The doctor will decide on the treatment based on the location of the cancer. If it is still confined to the prostate gland, a local treatment different from the first is usually recommended. If the cancer has spread beyond the prostate gland, you would need hormonal therapy.

TIPS FOR TALKING TO YOUR DOCTOR

(Adapted from “Making the Choice: Deciding What to Do About Early Stage Prostate Cancer”, by the Michigan Cancer Consortium).

1. Let the doctor know when things are confusing you.
2. Ask the doctor to slow down
 - a. and explain things differently
 - b. so that you will be able to explain things to your loved ones
 - c. so that you can take notes
3. To help you remember the details of your visit, bring
 - a. a loved one
 - b. a list of questions
 - c. this booklet (write down your questions on page 36 - 38)
4. Ask questions
5. Make your wishes known. Let the doctor know your preferences
6. Ask your doctor about the side effects you care most about.
7. Let the doctor know your other health problems.
8. Get a second opinion.
 - a. Ask for a referral to see a different kind of specialist (oncologist).
 - b. Speak to your regular primary care doctor.

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