# Breast Cancer





**Hong Kong Cancer Fund** was established in 1987 to provide support, information and care to those living with cancer and to increase awareness and knowledge of cancer in our community.

Our **CancerLink Care Centres** offer professional support and connect various cancer patient support groups to form an extensive support network for cancer patients and families, offering emotional support and practical assistance to those touched by cancer.

This publication is one in a series of cancer information booklets which discuss different aspects of the disease, including possible treatment, side effects and emotional issues. They are intended to inform the public about available treatment and care. You can also download the information from our website: www.cancer-fund.org.

The free services offered by **Hong Kong Cancer Fund** are made possible only because of donation from the public. If you would like to show your support and concern for cancer patients, please feel free to contact us. Your generosity will directly benefit cancer patients in Hong Kong. You can also use our donation form at the back of this booklet to make your contribution.

For further information on our services and our work,

Please call our

CancerLink Hotline: 3667 3000 (Hong Kong) 3656 0800 (Kowloon)

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www.cancer-fund.org

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This booklet has been prepared to help you understand more about breast cancer.

Many people feel understandably shocked and upset when told they have breast cancer. We hope this booklet will help you understand the diagnosis and treatment of the disease. We also include information about support services.

We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this booklet will answer some of your questions and help you think about the questions you want to ask your doctors.

You do not need to read it from cover to cover, just read the parts which are useful to you.

You may like to pass this booklet on to your family and friends for their information. They, too, may want to be informed so that they can help you cope with any problems you may have.

# What is Cancer?

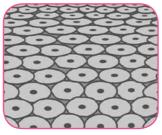
Cancer is a disease of the cells, which are the body's basic building blocks. Cancer starts in our genes. Our bodies constantly make new cells to enable us to grow, to replace worn-out cells, or to heal damaged cells after an injury. Certain genes control this process.

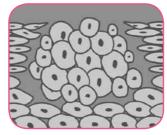
All cancers are caused by damage to these genes. This damage usually happens during our lifetime, although a small number of people inherit a damaged gene from a parent. Normally, cells grow and multiply in an orderly way. However, damaged genes can cause them to behave abnormally. They may grow into a lump called a tumour.

Tumours can be benign (not cancer) or malignant (cancer). 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. This is known as 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, becoming invasive cancer.

Some benign tumours are precancerous and may progress to cancer if left untreated. Other benign tumours do not develop into cancer.





Normal cells

Cells forming a tumour

# **How Cancer Spreads?**

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, either by the local tissue fluid channels (lymphatics) or in the blood stream, 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.

# **The Breasts**

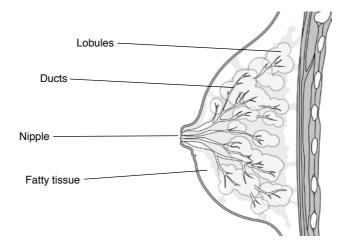
Both men and women have breasts. However, women's breasts are different because they are designed to make milk after pregnancy.

Breasts are made up of milk glands. The milk gland consists of two main parts:

- milk sacs called lobules
- tubes called ducts that take milk to the nipples.

Breasts also contain supportive fibrous tissue, fatty tissue and lymph vessels.

Lymph vessels carry a clear fluid called lymph. Most lymph vessels in the breast lead to lymph nodes under the arm. Breast cancer spreads to other parts of the body through the lymph and blood.





# **Symptoms**

It is common for women's breasts to change. Some changes happen every month - a woman's breasts may become swollen and tender during her periods. Breasts also change when you are pregnant or breastfeeding.

# Breast changes to look out for (including armpits):

- a lump, lumpiness, or feeling of thickness, somewhere in your breast
- anything coming out of your nipple without squeezing, except breast milk
- getting dimples in your breast
- pain in a part of your breast
- a change in the shape
- a nipple that turns in (unless it has always been turned in).

These changes do not mean you have breast cancer. Nine times out of ten, breast changes are not cancer.

# Common symptoms of non-cancerous breast changes include:

- cysts sacs of fluid which build up in the breast tissue
- fibroadenomas solid tumours made up of fibrous and glandular tissue.

However, if you do have any of these changes, see your doctor, just to make sure.

Breast cancer develops when some of the cells in the breast start to grow out of control. When this happens, a cancerous growth begins to appear somewhere inside the breast.

Most breast cancers begin in the lining of the ducts though a small number start in the milk sacs. If not treated, cancer cells from the breast can spread to other parts of the body.

There are about ten different kinds of breast cancer. Some grow slowly while others develop faster.

#### **Causes**

The causes of breast cancer are unknown. Factors that are known to increase the chance of developing breast cancer include:

 being older - more than half the women who are diagnosed with breast cancer are over 50.

- having a close relative, like a mother, sister or daughter who was diagnosed with breast cancer
- not having children
- having your first child when you are over 35
- drinking large amounts of alcohol
- periods that start very young or stop later than usual

Having several of these risk factors does not mean that you will get breast cancer. Most women with breast cancer have no known risk factors.

# How common is it in Hong Kong?

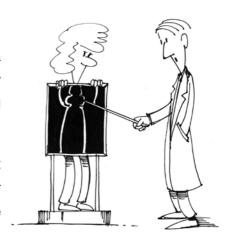
- Breast cancer is the most common cancer among women in Hong Kong
- Breast cancer ranks as the number 3 killer among female cancer
- There were 3,508 new breast cancer cases in 2012
- There were 601 people died of breast cancer in 2012
- Most breast cancer occur in women over 50 years of age, but in recent years, many younger women also start to develop breast cancer
- Men can develop breast cancer but it is rare (one in every 100)

source: Hong Kong Cancer Registry, Hospital Authority, 2012



If you or your doctor have found a breast change in your breast, your doctor will examine your breast and ask about your family history.

If your doctor thinks the breast change could be cancer, a number of tests will be done to confirm the diagnosis.



#### Various tests

#### **Mammogram**

This is an x-ray of the breast. The breast is flattened between two plates of the x-ray machine. You may find this uncomfortable and a little painful.

A mammogram gives the doctor more information about any lump or other changes.

#### Ultrasound

Uses sound waves to help find lumps or other changes in the breast.

A gel is spread over your breast and a small microphone is moved over the skin.

### Biopsy

If a lump is detected on a mammogram or ultrasound a biopsy will be taken.

Part of the lump from the area of change will be removed and examined under a microscope.

#### A biopsy is done in several ways:

#### fine needle aspiration

Cells from the lump are taken out with a thin needle. It is like having blood taken for a blood test. It may be a little uncomfortable but is not painful.

#### core biopsy

A larger needle is used with a local anaesthetic.

#### open biopsy

The whole lump is taken out. This is usually done with a general anaesthetic, so that you are asleep while it is going on.

#### **Further tests**

If the breast change turns out to be cancer, more tests may be done.

A bone scan, chest x-ray and blood tests maybe done to check that the cancer has not spread to these parts of your body.



Treatment for breast cancer depends on what part of the breast the cancer is in, how fast it is growing, whether it has spread, your age and state of health. Your own preferences will also be considered.

Most breast cancers are treated either by:

Surgery Radiotherapy Chemotherapy Hormone treatment

You may have one of these treatments or a combination.

# Surgery

Your doctor will discuss with you the most appropriate type of surgery, depending on the size and any spread of the cancer. Before any operation, make sure that you have discussed it fully with your doctor. Remember, no operation or procedure will be done without your consent.

If a diagnosis of breast cancer has already been made, either by needle aspiration or biopsy, the surgeon can discuss your operation with you in advance.

Sometimes a definite diagnosis cannot be made before the operation and the surgeon will need to remove the lump so it can be examined under a microscope.

The lump is removed and examined later. If it is necessary, a further operation can be arranged for a few days afterwards. This allows you more time to prepare yourself.

In the past, the usual way of doing this operation involved removing the lump to be examined under a microscope while the patient was still under anaesthetic. To do this, the lump was frozen and this was, therefore, called a frozen section. If the lump was malignant and a further operation was necessary, the surgeon did it immediately. Nowadays, this is a rare procedure. Most surgeons agree a frozen section is of no more benefit than waiting a few days for the result, giving the woman more time to prepare herself if a further operation is necessary.

For many women it is now possible to have smaller operations to conserve the breast rather than a mastectomy. All breast surgery, however, will leave some type of scar, and the cosmetic effect depends on the technique used. It is usually possible to discuss with the doctor or nurse beforehand what your breast will look like after surgery.

#### Lumpectomy

This is the removal of the breast lump together with some surrounding tissue. A lumpectomy is now possible for many women. It removes the least amount of breast tissue, but leaves a small scar and sometimes a small dent in the breast. For most women, the appearance of the breast after lumpectomy is good.

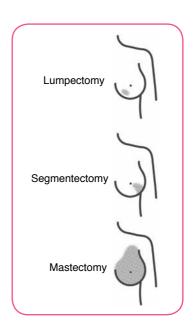
# | Segmentectomy (wide local excision)

This is similar to a lumpectomy but as it involves removing more breast tissue, then it may be more noticeable, particularly in women who have small breasts. In women with large breasts it is usually less noticeable.

# Mastectomy

A mastectomy removes the whole breast, including the skin and the nipple. Usually the lymph nodes in the armpit are also removed during the operation. This is called axillary clearance or dissection.

After mastectomy, most women have a horizontal scar across their chest. Other side effects include: infection, a reduced sensitivity

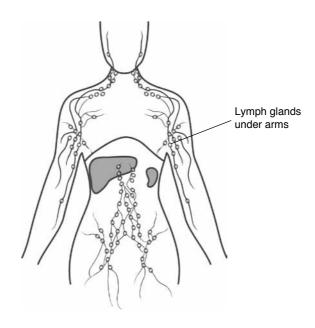


due to nerve damage and swelling of the arm (lymphoedema). Improvements in surgical techniques have made these side effects less common.

For many women the breast can be reconstructed after surgery.

# Lymph gland removal

With any of these operations, the surgeon will usually remove lymph glands from under your arm. This is done to check whether any cancer cells have spread from the breast and helps doctors decide whether other treatment is needed. Some doctors remove all the armpit lymph glands, while others take just a few lymph glands as a representative sample.



# What is lymphoedema?

Removing the lymph nodes affects the drainage of the lymph. This can cause the arm to swell and go puffy. Radiotherapy to the lymph nodes under the arm can also have this effect. Leaving the lymph nodes in, increases the risk of the cancer appearing later in the lymph nodes.

#### Breast reconstruction

After a mastectomy the breast can be reconstructed in the following ways:

### 1. A prosthesis

This can be a piece of specially made foam or liquid-filled sac that is shaped to form a sort of artificial breast that fits into your bra. It can also be surgically implanted into the chest wall.

#### 2. Breast is reconstructed from your own tissue

The tissue is taken from the normal breast or skin and fat from the back or, occasionally, the abdomen.

Sometimes the breast reconstruction can be started at the same time as the mastectomy. It would not be completed at that time - a breast reconstruction involves several operations.

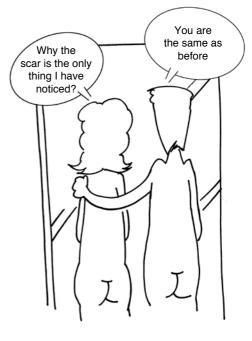
# Living with breast surgery

Breast cancer surgery, whether it removes all of your breast, or only a part of it, can be a deeply traumatic experience. You may feel that your breasts are very important to your idea of yourself as a woman and find that the alteration to your appearance severely affects your self-confidence. Many women need time to come to terms with that loss.

All women find different ways of trying to come to terms with their altered bodies. Some prefer to see the results of the surgery for the first time alone. Others may want the support of a partner or close friend, or doctor or nurse, when they take their first look. Either way, the first few months are likely to be very upsetting and many women are swamped with conflicting emotions. Grief, fear, shock, anger and resentment mixed, perhaps, with relief that the cancer has been found and treated - women have felt all or some of these to varying extents as they start to live with the effects of breast cancer surgery.

Help is available though. No woman has to deal with this experience alone, unless she prefers to do so. Many hospitals have specially trained counsellors who are expert in supporting women at this time. Doctors, too, often have wide experience of helping women through this traumatic situation. The support of a caring partner or close friend can also be invaluable. Hong Kong Cancer Fund (tel: 3656 0800) has an excellent volunteer support programme and can put you in touch with women in your area who had been similar experience and they can offer comfort and practical advice.

Although breast surgery will not affect your physical ability to have sex, it is obvious that the accompanying strong emotions may in some way alter your sexual feelings for a while. At any age, women need



to feel relatively happy with their bodies to have a fulfilling sex life. Fear that a partner - even a longstanding one - may be put off by the result of the surgery can make women fearful of the moment they allow someone to see or touch their body.

When and how to start an intimate relationship with your partner, does not have a set timetable, it all depends on your own feeling and the rapport with your partner. Hong Kong Cancer Fund published a booklet on 'Cancer and Sexuality', We are happy to send it to you upon request. Please call 3667 3000.

Some women feel so vulnerable, they need time simply to be alone to try to comfort themselves and build up the courage to face someone else - even a deeply loved partner. Others need almost immediate physical comfort and find loving touch a powerful relief to the fear of rejection. Letting someone else see their changed appearance is, for many women, the first step in coming to terms with their situation.

Comforting words which may seem trite at first - such as, it will get better with time - are actually true. Although, if you have had a mastectomy, only a reconstruction operation will restore a breast, swelling will go down, bruising soon fades and scars will gradually become less obvious. As you become more used to the soft breast prosthesis, this will also help to restore your confidence.

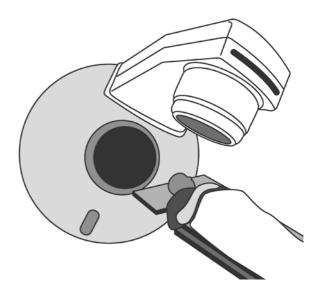
The aftermath of breast cancer surgery can leave you emotionally and physically drained. Try to allow yourself to grieve for as long as you need and to enlist the caring support of others whenever and in whatever way is best for you.



# **Radiotherapy**

Radiotherapy uses x-rays to kill cancer cells.

Radiotherapy may be used after breast-conserving surgery to kill any cancer cells left behind. It may used after a also be mastectomy. The x-rays



are carefully aimed to avoid damaging normal cells nearby.

Following radiotherapy your breasts may feel slightly firmer and may change a little in size or shape.

Two main types of radiotherapy are used to treat breast cancer: external radiotherapy and internal radiotherapy.

# External radiotherapy

This is given as a course of treatment in the hospital radiotherapy department. The treatment is usually given five days a week over about six weeks. It does not hurt and only takes a few minutes. The length of your treatment will depend on the type and size of the tumour and your doctor will discuss this with you. Whenever possible, treatment is given as an out-patient,

but if you are already an in-patient you will be taken to the radiotherapy department each day from the ward. For a few women, this type of radiotherapy is the only form of treatment needed to treat their breast cancer. More usually it is given as a back-up to surgery, after a lumpectomy, segmentectomy or mastectomy.

External radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, after your treatment.

#### Planning your treatment

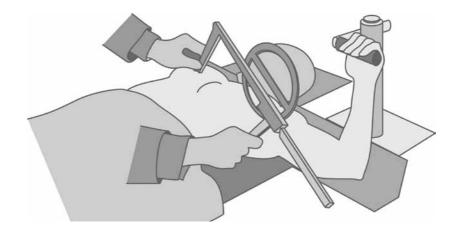
To ensure that you receive maximum benefit from your radiotherapy it has to be carefully planned.

On your first visit to the radiotherapy department you may be asked to lie under a machine called a simulator which takes X-ravs of the area to be treated. Treatment planning is a very important part of radiotherapy and it may take a few visits before the radiotherapist or doctor who plans your treatment, is satisfied with the result.

Marks may be drawn on your skin so that the radiotherapist can direct the rays to the treatment area. During the course of treatment this area should be kept as dry as possible to prevent the skin from becoming sore and to keep the marks visible.

Advice about skin care may vary from one hospital to another. Some departments will tell you not to wash the treatment area at all, for the time you are having treatment. Others will advise you to use only tepid water to wash the area, and then to dry it by patting gently with a soft towel. Do not rub the area, as this may make it sore. Perfumed soaps, talc, deodorants, lotions and perfumes may also make your skin sore and should not be used.

Before radiotherapy is given, that the radiotherapist will position you carefully on the couch and make sure that you are comfortable. During your treatment, which only takes a few minutes, you will be left alone in the room but you will be able to talk to the radiotherapist who will be watching you carefully from an adjoining room. Radiotherapy is not painful, but you do have to stay still for several minutes while your treatment is being given.



### Internal radiotherapy

This type of radiotherapy is sometimes given as a back-up after lumpectomy or segmentectomy. It is given by implanting wires containing a radioactive substance into the breast under a general anaesthetic. This gives an extra dose of radiation to the area surrounding the tumour.

During this time you will need to stay in hospital and will be nursed in a separate room. The amount of time your visitors and the nursing staff can spend with you may be restricted to prevent them being unnecessarily exposed to radiation, but children and pregnant women will not be allowed to visit you at all. Radioactivity disappears once the wires are removed, and it is then perfectly safe for you to be with other people and children.

#### Side effects of Radiotherapy

Radiotherapy can cause temporary side effects, including:

- tiredness and nausea
- mild headaches
- skin in the treatment area may become red and sore

Side effects can be helped with medication and usually go away once treatment is finished.

If you are concerned about the risk of developing particular

side effects from radiotherapy, you should speak to your radiotherapist.

Hong Kong Cancer Fund published a booklet on 'Radiotherapy'. To request the booklet please call CancerLink on 3667 3000

# Chemotherapy

Chemotherapy drugs are given by injection into a vein (intravenously) or as tablets. Chemotherapy into the vein is given as a session of treatment, which usually lasts for less than a day. This is followed by a rest period of a few weeks, which allows your body to recover from any side effects of the treatment.

There are many different chemotherapy drugs, and combinations of drugs, used to treat breast cancer. You may be offered a choice of treatments, as the different combinations have different side effects.

Chemotherapy is usually given to you as an outpatient. A complete course of chemotherapy is likely to take 4-6 months.

# Benefits of chemotherapy

In women whose cancer is very unlikely to come back, chemotherapy may only reduce the chance of recurrence by a small amount. In women where the chance of the cancer coming back is higher, chemotherapy may greatly reduce the chance of recurrence. Your doctor can let you know how likely chemotherapy is to make a difference in your case. They can also let you know about the possible side effects.

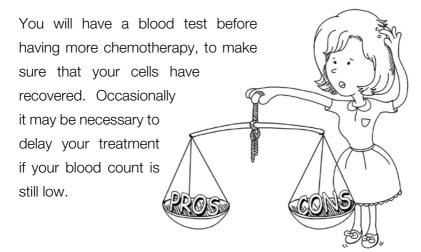
# Side effects of chemotherapy

Chemotherapy drugs can cause side effects, but these can usually be well controlled with medicine.

#### Lowered resistance to infection

Chemotherapy can reduce the production of white blood cells by the bone marrow, making you more prone to infection. Contact your doctor or the hospital straightaway if:

- Your temperature goes above 38°C (100.5°F).
- · You suddenly feel ill (even with a normal temperature).



#### Bruising or bleeding

Chemotherapy can reduce the production of platelets, which help the blood to clot. Let your doctor know if you have any unexplained bruising or bleeding.

#### Anaemia (low number of red blood cells)

You may become anaemic. This may make you feel tired and breathless.

#### Nausea and vomiting

Some chemotherapy drugs can make you feel sick or even be sick. This can be helped by taking anti-sickness drugs (anti-emetics) which your doctor can prescribe.

#### Sore mouth

Some chemotherapy drugs can make your mouth sore and may cause small ulcers. Regular mouthwashes are important and the nurses will show you how to do these properly.

#### Poor appetite

If you do not feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet.

#### Hair loss

It is a common side effect of some chemotherapy drugs. This

can be very distressing for some people. However, there are many ways of covering up hair loss, including the using of wigs, hats or scarves. If your hair does fall out, it should start to grow back within about 3-6 months of the end of treatment. Hong Kong Cancer Fund has published a booklet on coping with 'Hair Loss' which discusses all the practical ways of dealing with hair loss and how to cope with the emotional effects. We are happy to send you one upon request. Please call 3667 3000.

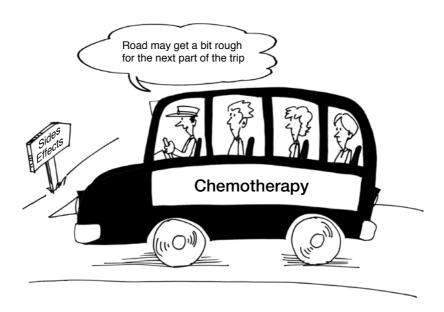
Chemotherapy affects people in different ways. Some people find that they are able to lead a fairly normal life during their treatment, but many people become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it.

Although these side effects may be hard to deal with at the time, they will gradually disappear once your treatment is over.

#### Early menopause

Some women may find that chemotherapy causes early menopause.

You will find more information on 'Chemotherapy' in the Understanding Cancer Booklets series. To request the English booklet, please call CancerLink on 3667 3000.



# Hormone therapy

Some breast cancers need the female hormone oestrogen to grow. Reducing the amount of oestrogen in your body can help slow down the growth of the cancer or even shrink it.

Some drugs can stop your body producing oestrogen. Others drugs such as Tamoxifen stop the cancer cells from using oestrogen.

# Follow- up

After your treatment is over, you will have regular checkups. Your doctor will decide how often you need checkups and who will do them, because everyone's situation is different.

It is important that all of the health professionals (who are part of a multidisciplinary team) who have been involved with your care are kept involved where necessary and aware of your ongoing progress. Checkups will less become frequent if you have no further problems.



If the disease relapses, you may need further treatment. Often, the treatment used when breast cancer relapses is different to the first treatment.

If you have any doubts about your recovery or follow-up, contact the staff who has provided your first treatment.

# Making treatment decisions

Sometimes it is difficult to decide on the right treatment for you. You may feel everything is happening so fast that you do not have time to think things through. There is always time for you to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed with information, others feel they do not have enough. You need to make sure you understand enough about your illness, the treatment and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh 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 offered.

It is important to remember that you are the most important person on your health care team. You are a consumer of services, and you have the right to ask questions about what treatment you are getting and who is providing it. If you are not happy with the information you are given - or how it is given -- you should not be afraid to tell the doctor about your concerns.

Some people with more advanced cancer will always choose

treatment, even if it only offers a small chance of cure. Others want to make sure 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 symptoms managed to maintain the best possible quality of life.

You always have the right to find out what a suggested treatment means to you, and the right to accept or refuse it.

# **Talking To Doctors**

You may want to see your doctor a few times before deciding on treatment. When your doctor first tells you that you have cancer, it is obviously very stressful and you may not remember very much.

- You may need to ask the same questions more than once.
- · Before you see the doctor, it may help to write down your auestions
- Taking notes during the session or tape-recording the discussion with the doctor's permission is also helpful

 Take a family member or friend with you. He or she can take part in the discussion, take notes or simply listen.

"I took a friend with me for support to the second appointment. It was like a dream where I just said 'yes, yes, yes', and luckily my friend wrote down all the information."

Many doctors are involved in treating people with breast cancer. If you are considering a particular treatment and want advice, you should see the specialist who delivers that treatment, such as the medical oncologist for chemotherapy and radiation oncologist for radiotherapy. The specialists who prescribe these treatments have the best information about the benefits and side effects of treatment in your situation. They are also aware of the latest clinical trials in breast cancer.

# **Talking with others**

Once you have discussed treatment options with your doctor, you

may want to talk them over with family or friends, nursing staff, the hospital social worker or chaplain, your own religious or spiritual adviser, or the CancerLink Hotline 3656 0800. Talking it over can help sort out the right course of action 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 decisionmaking process. A second opinion can confirm or suggest changes to your doctor's recommended treatment plan, reassure you that you have explored all of your options, and answer any questions you may have.

Your specialist or family doctor can refer you to another specialist and you can ask for your results to be sent to the second-opinion doctor. You may later decide you prefer to be treated by the doctor who provided the second opinion, and this is your right.

You can ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.

# Can I still have children?

Recent research suggests that pregnancy does not make a recurrence of breast cancer more likely.

If you do want to have a child, you and your partner should discuss this with your doctor, who knows your full medical history, and talk over the risks and implications. It would be advisable to wait a while after your initial treatment has finished before trying to become pregnant. The longer you remain free of disease, the less likely it is that the cancer will recur; but you should probably consider carefully what might happen if, after having a baby, the cancer did come back, and whether you are both prepared to take the risk of that extra responsibility.

Unfortunately, women who have had radiotherapy to their ovaries, an operation to remove their ovaries or some types of chemotherapy will no longer be able to have children.

This added blow can be very hard for some women to live with - whether or not they already have children. Fertility is a very important part of many people's lives and not being able to have children can seem especially hard when you are already having to cope with cancer. Some people find it helpful to talk through their feelings about this distressing situation. CancerLink (Tel: 3667) 3000) can put you in touch with trained counsellors or support group.

Loss of fertility is not usually something people can come to terms with in a short time. Allow yourself time to adjust to it and to express your sadness that a part of your life and a natural function of your body has been denied you. When you feel ready, talking with your partner, family or close friend may help you cope. Do not be afraid to ask your doctor for professional help. This is in no way a failure. People will understand that, whatever your circumstances, infertility is a situation with which most people cannot easily cope alone.

# **Ontraception**

As the cancer may be affected by hormones, women who have had breast cancer are usually advised not to take the contraceptive pill. Recently there has been some evidence to suggest that giving the combined oestrogen and progesterone pill may be less likely to cause any problem than oestrogen alone.

Barrier methods of contraception such as condoms or the cap are suitable. KY jelly and baby oil (available without prescription from the chemist) are completely safe to use with barrier contraceptives if extra moisture is needed during sex.

Your doctor can give you good contraceptive advice, who can also fit you for a cap if this is the contraceptive you choose. Coils (IUDs) are also effective but not the ones that work by secreting progesterone, another female hormone. Again, your doctor can fit you with a coil if you wish. Some women choose to be sterilised to prevent the risk of pregnancy.

# What to ask doctors?

You may find the following checklist helpful when thinking about the questions to ask your doctor. If there are answers you do not understand, it is alright to ask your doctor to explain again.

#### Some suggested questions are listed below:

- 1. What type of breast cancer do I have?
- 2. How extensive is my cancer?
- 3. What treatment do you recommend and why?
- 4. Will a doctor who specialises in breast cancer give my treatment?
- 5. Are all modern investigations and treatments for my type of cancer available in this hospital?
- 6. Are there other treatment choices for me?
- 7. Are there any clinical trials of new treatments?
- 8. What are the risks and possible side effects of each treatment?
- 9. Will I have to stay in hospital, or will I be treated as an outpatient?
- 10. How long will the treatment take? How much will it affect what I can do?
- 11. How much will it cost?
- 12. Will I have a lot of pain with the treatment? What can be done about this?
- 13. If I need further treatment, what will it be like and when will it begin?
- 14. Will the treatment affect my sex life?

- 15. Will I be able to have children after the treatment?
- 16. How frequently will I have checkups and what will they involve?
- 17.1 would like to have a second opinion. Can you refer me to someone else?
- 18. Am I going to survive? How long will I live?





Most people feel overwhelmed when they are told they have cancer. Many different emotions arise which can cause confusion and frequent changes of mood. You might not experience all the feelings discussed below or experience them in the same order. This does not mean, however, that you are not coping with your illness. Reactions differ from one person to another - there is no right or wrong way to feel. These emotions are part of the process that many people go through in trying to come to terms with their illness. Partners, family members and friends often experience similar feelings and frequently need as much support and guidance in coping with their feelings as you do.

# **General feelings**

#### Shock and disbelief

#### "I can't believe it". "It can't be true".

This is often the immediate reaction when cancer is diagnosed. You may feel numb, unable to believe what is happening or to express any emotion. You may find that you can take in only a small amount of information and so you have to keep asking the same questions over and over again, or you need to be told the same bits of information repeatedly. This need for repetition is a common reaction to shock. Some people may find their feelings of disbelief make it difficult for them to talk about illness with their family and friends, while others feel an overwhelming urge to discuss it with those around them; this may be a way of helping them to accept the news themselves.

#### Denial

"There's nothing really wrong with me". "I haven't got cancer".

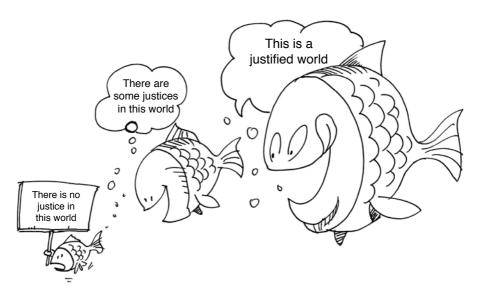
Many people cope with their cancer by not wanting to know anything about their cancer, or not wanting to talk about it. If that is the way you feel, then just say quite firmly to the people around you that you prefer not to talk about your illness, at least for the time being.

Sometimes, however, it is the other way round. You may find that it is your family and friends who are denying your illness. They appear to ignore the fact that you have cancer, perhaps by playing down your anxieties and symptoms or deliberately changing the subject. If this upsets or hurts you because you want them to support you by sharing what you feel, try telling them that you do know what is happening and that it will help you if you can talk to them about your illness.

### Anger

### "Why me?" "Why now?"

Anger can hide other feelings such as fear or sadness. You may be feeling angry out on those who are closest to you and on the doctors and nurses who are caring for you. If you have a religious faith you may feel angry with your God.



It is understandable that you may be deeply upset by many aspects of your illness and you should not feel guilty about your angry thoughts or irritable moods. Relatives and friends though may not always realise that your anger is really directed at your illness and not against them. If you can, it may be helpful to tell them this at a time when you are not feeling quite so angry. If you find that difficult, perhaps you could show them this page of the booklet. If you are finding it difficult to talk to your family, it may help to discuss the situation with a trained counsellor or psychologist. Hong Kong Cancer Fund can give you details of how to get this sort of help in your area. Please contact 3656 0800.

## Fear and uncertainty

"Am I going to die?" "Will I be in pain?" "Will the cancer come back?"

Cancer is a frightening word surrounded by fears and myths. One of the greatest fears expressed by almost all newlydiagnosed patients is: "Am I going to die?"

In fact, nowadays many cancers are curable if caught at an early enough stage. This is especially true of breast cancer.

Even if the cancer is not completely curable, modern treatments often mean that the disease can be controlled for years and many patients can live an almost normal life.

"Will I be in pain?" and "Will my pain be unbearable?" are other common fears. In fact, many cancer patients experience no pain at all. For those who do, there are many modern drugs that are very successful in relieving pain or keeping it under control.

Many people are anxious about their treatment; whether or not it will work and how to cope with possible side effects. It is best to discuss your individual treatment in detail with your doctor. Make a list of questions which you may want to ask and do not be afraid to ask your doctor to repeat any answers or explanations you do not understand. You may like to take a close friend or relative to the appointment with you. If you are feeling upset, they may be able to remember details of the consultation which you might have forgotten or you may want them to ask some of the questions you do not want to ask. Some people are afraid of the hospital itself. It can be a frightening place, especially if you have never been in one before, but talk about your fears to your doctor, he or she should be able to reassure you.

You may find the doctors cannot answer your questions fully, or that their answers sound vague. It is often impossible to say for certain that they have got rid of the cancer completely. Doctors know from past experience approximately how many people will benefit from a certain treatment. It is impossible to predict the future for individual people. Many people find this uncertainty hard to live with; not knowing whether or not you are cured can be disturbing.

Uncertainty about the future can cause a lot of tension, but fears are often worse than the reality. Fear of the unknown can be terrifying so finding out about your illness can be reassuring. Discussing it with your family and friends can help to relieve tension caused by unnecessary worry.

### Blame and guilt

#### "If I hadn't...this would never have happened".

Sometimes people blame themselves or other people for their illness, trying to find reasons for why it should have happened to them. This may be because we often feel better if we know why something has happened. As doctors rarely know exactly what has caused your cancer, there is no reason for you to blame yourself.

#### Resentment

### "It's all right for you, you have not got to put up with this."

Understandably, you may be feeling resentful and miserable because you have cancer while other people are well. Similar feelings of resentment may crop up from time to time during the course of your illness and treatment for a variety of reasons. Relatives too can sometimes resent the changes that the patient's illness makes to their lives.

It is usually helpful to bring these feelings out into the open so that they can be aired and discussed. Bottling up resentment can make everyone feel angry and guilty.

#### Withdrawal and isolation

#### "Please leave me alone"

There may be times during your illness when you want to be left alone to sort out your thoughts and emotions. This can be hard for your family and friends who want to share this difficult time with you. Reassure them that although you may not feel like discussing your illness at the moment, you will talk to them about it when you are ready.

### | Depression

Sometimes depression can stop you wanting to talk. It may be an idea to discuss this with your GP who can prescribe a course

of antidepressant drugs or refer you to a doctor who specialises in the emotional problems of cancer patients. It is common for women with breast cancer to feel depressed, so there is no need to feel you are not coping if you ask for help.



# Learning to cope

After any treatment for cancer it can take a long time to come to terms with your emotions. Not only do you have to cope with the knowledge that you have cancer but also the physical effects of the treatment.

The treatment for breast cancer can cause unpleasant side effects but some women do manage to lead an almost normal life during their treatment. Obviously you will need to take time off for your actual treatment and some time afterwards to recover. Just do as much as you feel like and try to get plenty of rest.

Do not see it as a sign of failure if you have not been able to cope on your own. Once other people understand how you are feeling they can be more supportive.

# What can you do?

Many people feel helpless when they are first told they have cancer and think there is nothing they can do other than hand themselves over to the doctors and hospitals. This is not so. There are many things you, and your family, can do at this time.



# **Understanding your illness**

If you and your family understand your illness and its treatment, you will be better prepared to cope with the situation. In this way you at least have some idea of what you are facing.

For information to be of value, it must come from a reliable source so as to prevent unnecessary fears. Personal medical information should come from your own doctor who is familiar with your medical background. As mentioned earlier, it can be useful to make a list of questions before your visit or take a friend or relative with you to remind you of things you want to know but can forget so easily.

# **Practical and positive tasks**

At times you may not be able to do things you used to take for granted. But as you begin to feel better you can set yourself some simple goals and gradually build up your confidence. Take things slowly and one step at a time.

Many people talk about 'fighting their illness'. This is a healthy response and you can do it by becoming involved in your illness. One easy way of doing this is by planning a healthy, well-balanced diet. Another way is to learn relaxation techniques that you can practise at home with tapes. Contact Hong Kong Cancer Fund for more information.

Many people find it helpful to take some regular exercise. The type of exercise you take, and how strenuous, depends on what you are used to and how well you feel. Set yourself realistic aims and build up slowly.

If the idea of changing your diet or taking exercise does not appeal to you, do not feel you have to do it; just do whatever suits you. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby.

## **Financial Support**

Cancer is serious illness. Many cancer patients will need to face not only side effects of the treatments and emotional trauma, but also financial difficulties. The disease can become a tremendous burden.

Apart from using the public health care services, the medical insurance and welfare provided by employers as well as Government hardship funds for the less well-off are all useful to cut down your medical expenses.

You may approach the medical social workers or Cancer Patients' Resource Centres in major hospitals for institutions that might be able to provide assistance. The 'Comprehensive Social Security Assistance' (CSSA) offered by the Social Welfare Department (SWD) may also solve your financial difficulties. For details please Call SWD hotline at 2343 2255.

Contact the medical social worker in your hospital or call our Hotline 3656 0800 for more information.

# Talking to children

Deciding what to tell children about cancer is difficult. How much you tell them will depend upon their age and how grown up they are. Very young children are concerned with immediate events. They do not understand illness and need only simple explanations of why their relative or friend has had to go into hospital. Slightly older children may understand a story explanation in terms of good cells and bad cells but all children need to be repeatedly reassured that the illness is not their fault because, whether they show it or not, children often feel they may somehow be to blame and may feel guilty for a long time. Most children of about 10 years old and over can grasp fairly complicated explanations.



Adolescents may find it particularly difficult to cope with the situation because they feel they are being forced back into the family just as they were beginning to break free and gain their independence. Daughters in particular may worry that their mother's illness can be passed on to them.

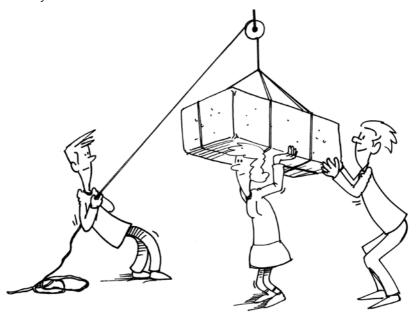
An open, honest approach is usually the best way for all children. Listen to their fears and be aware of any changes in their behaviour. This may be their way of expressing their feelings. It may be better to start by giving only small amounts of information and gradually building up a picture of the illness. Even very young children can sense when something is wrong so do not keep them in the dark about what is going on. Their fears of what it might be are likely to be far worse than the reality.

Hong Kong Cancer Fund published a booklet on 'What Do I Tell the Children?' which may be able to help you. To request for an English copy, please call CancerLink 3667 3000.



# What to do if you are a relative or friend?

Some families find it difficult to talk about cancer or share their feelings. The first reaction of many relatives is that the patient should not be told that she has cancer. They may be afraid that the patient will be unable to cope with the news. If a decision is made not to tell, the family then has to cover up and hide information. These secrets within a family can be very difficult to keep and they can isolate the person with cancer. This can make her more frightened and can cause tension between family members. In any case, many people suspect their diagnosis, even if they are not actually told.



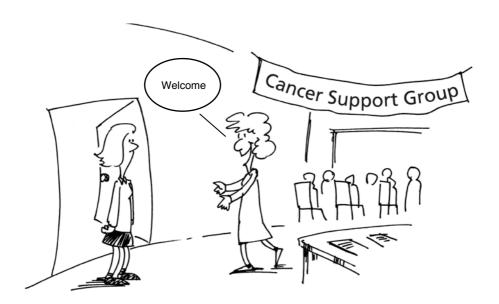
Whether you are the person with cancer or a close relative, friends and relatives, with a positive attitude are always more helpful than the gloomy, pessimistic ones.

Relatives and friends can help by listening carefully to what, and how much, the person with cancer wants to say. Do not rush into talking about the illness. Often it is enough just to listen and let the person with cancer talk when she is ready.

You will find more information in our booklet on "Talking to Someone with Cancer" in the How to Cope series. It aims at some of the difficulties people may have when talking about cancer. To request the booklet, please call our hotline: 3667 3000.

# Who can help?

The most important thing to remember is that there are people available to help you and your family. Often it is easier to talk to someone who is not directly involved with your illness. You may find it helpful to talk to a counsellor who is specially trained to offer support and advice. Many people also find great comfort in their religion at this time. Hong Kong Cancer Fund is always willing to discuss any problems that you might have and we can put you in touch with a counsellor or a support group.



### **Hong Kong Cancer Fund Service Network**

Our six "Cancer Patients' Resource Centres" in major public hospitals and the two CancerLinks Support Centres in the community provide free counselling, support and information to those in need. Together they form a seamless service network that meet the needs of those living with cancer at different stages of their cancer journey. For directory, please see page 39.

#### ■ Cancer Patients' Resource Centres

There are altogether six Cancer Patients' Resource Centres within the oncology departments of the major public hospitals. They are often the first point of contact for support and information after a diagnosis. The centres provide cancer information, emotional support, counselling and guidance to those in need.

#### CancerLinks

We have two care centres outside the hospital setting which cater to the specific needs of cancer patients throughout different stages of their diagnosis. CancerLink Central offers a well designed holistic rehabilitation programme which emphasizes individual needs while CancerLink Wong Tai Sin is the home to 14 support groups and is the centre for peer sharing and group activities.

Care specialists including registered social workers, oncology nurses, counsellors and therapists are on board to provide support, information and specialised services.

Programmes in our care centres are carefully designed to meet different needs. Private and group counselling are conducted by registered professionals to help patients and families deal with different emotional aspects during their course of treatment. There are also courses to develop coping skills, relaxation classes to help relieve mental and physical stress, and peer support groups for experience sharing. There is also a well-stocked library in each centre, with rehabilitation equipment ready for use or loan.

Whether you are seeking self-help information or group support, choices are always available.

#### ■ Hotline

Our hotline receives thousands of calls every year. It is supervised by professionals who share and give advice on both physical

and emotional difficulties faced by patients and their families. Talking with someone who understands can make a huge difference.

Hotline: 3667 3000 (Hong Kong)

3656 0800 (Kowloon)

# **Care in Action**

We provide free information and counselling

Hotline: 3667 3000 (Hong Kong) 3656 0800 (Kowloon)

Website: www.cancer-fund.org

