

# Understanding cancer of the bladder

This booklet is for you if you have or someone close to you has cancer of the bladder.

It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. Together they represent an agreed view on this cancer, its diagnosis and management, and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you. You can make a note below of the main contacts and information that you may need quickly.

**Specialist nurse/contact names**

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**Hospital**

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.....  
.....

**Phone** .....

**Treatments** .....

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**Family doctor**

.....  
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**Surgery address**

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.....  
.....

**Phone** .....

**Review dates**.....

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.....

*If you like, you can also add:*

**Your name** .....

**Address** .....

# Understanding cancer of the bladder – key points in this booklet

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This booklet aims to tell you about cancer of the bladder, how it is diagnosed and treated and how the treatment may affect you.

These two pages sum up the main points, and show which pages to turn to for more information.

## What are the different types of cancer of the bladder? Page 8

There are three different types of cancer of the bladder:

- papillary or superficial
- carcinoma in situ
- invasive

## What are the causes of cancer of the bladder?

Page 9

The main known causes of cancer of the bladder are:

- cigarette smoking
- more rarely, exposure to chemicals used in dye factories and certain chemical industries

## What are the symptoms of cancer of the bladder?

Page 10

The commonest symptom is blood in the urine.

Other symptoms are a burning feeling when passing urine, and a need to pass urine more often than usual.

**However, these symptoms are common to many other conditions, not just cancer.**

## How is cancer of the bladder diagnosed? Pages 11-14

Various tests are used, including

- blood tests
- intravenous urogram
- chest x-ray
- cystoscopy and biopsy

## **What types of treatment are used?** Pages 14-28

The type of treatment depends on whether the cancer is superficial or has spread into the wall of the bladder (invasive) or beyond. Surgery, radiotherapy, chemotherapy (given either directly into the bladder or intravenously) and immunotherapy (given directly into the bladder) can be used, either on their own or in combination.

## **How will I feel during and after treatment?**

Pages 30-35

You may feel anxious, afraid or angry because of the cancer, the treatment and its effects.

The worst fear is often fear of the unknown. It may help you to find out as much as you can about the cancer, its treatment, and living with it.

Do not be afraid to ask, and go on asking until you get the information and support you need.

## **For more information**

Many people and organisations can help. This booklet lists useful organisations (pages 42-44), books that might help (pages 45-46), and has a page for you to write down any questions you might want to ask your doctor or nurse, with the answers you receive (facing inside back cover). CancerBACUP information is available on the Internet ([www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)).

The nurses in CancerBACUP's cancer information service (0171 613 2121 or Freephone 0800 800 1234) can give information about all aspects of cancer, and people who can help.

CancerBACUP information is available on our website [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk), and on a CD-ROM – for details, phone 0171 696 9003.



*Helping people  
live with cancer*

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London EC2A 3DR

CancerBACUP was founded by Dr Vicky Clement-Jones, following her own experiences with ovarian cancer, and offers information and support to people with cancer, their families and friends.

We produce publications on the main types of cancer, treatments, and ways of living with cancer. We also produce a magazine, *CancerBACUP News*, three times a year.

Our success depends on feedback from users of the service. We thank everyone, particularly patients and their families, whose advice has made this booklet possible.

Administration 0171 696 9003

Cancer Support Service:

0171 613 2121 (8 lines) or Freephone 0808 800 1234

CancerBACUP Scotland

0141 553 1553 (Glasgow)

CancerBACUP Nottingham

0115 840 2650

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# Introduction

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This information booklet has been written to help you understand more about cancer of the bladder. We hope it answers some of the questions you may have about its diagnosis and treatment, and addresses some of the feelings which are a large part of anyone's reaction to a cancer diagnosis.

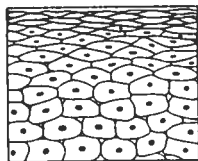
We can't advise you about the best treatment for yourself because this information can only come from your own doctor, who will be familiar with your full medical history.

At the end of this booklet you will find a list of other CancerBACUP publications, some useful addresses and recommended books, and a page to fill in with your questions for your doctor or nurse. If, after reading this booklet, you think it has helped you, do pass it on to any of your family and friends who might find it interesting. They too may want to be informed so they can help you cope with any problems you may have.

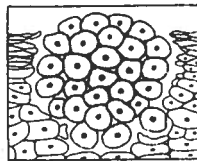
## What is cancer?

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The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Although cells in different parts of the body may look and work differently, most repair and reproduce themselves in the same way. Normally, this division of cells takes place in an orderly and controlled manner. If, for some reason, the process gets out of control, the cells will continue to divide, developing into a lump which is called a **tumour**. Tumours can be either **benign** or **malignant**.



Normal cells



Cells forming a tumour

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. If they continue to grow at the original site, however, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells which have the ability to spread beyond the original site. If the tumour is left untreated, it may invade and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer and spread to other organs in the body through the bloodstream or lymphatic system. When these cells reach a new site they may go on dividing and form a new tumour, often referred to as a **secondary** or a **metastasis**.

Doctors can tell whether a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a biopsy.

It is important to realise that cancer is not a single disease with a single cause and a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

## The bladder

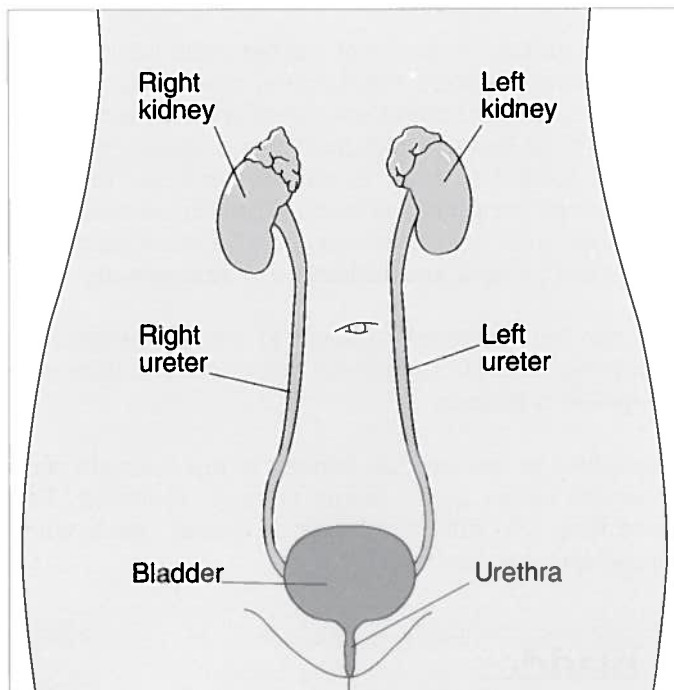
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The bladder is a hollow, muscular, balloon-like organ that collects and stores urine. It is situated in the lower part of the abdomen. Urine consists of water and waste products not needed by the body.

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

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

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



## What are the different types of cancer of the bladder?

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Nearly all cancers of the bladder are found in the lining (**urothelium**) of the bladder. These are called **transitional cell** or **urothelial cell** cancers. They come in a very wide range of forms and can behave in very different ways. For example, one type may occur as a small wart-like growth on the inside of the bladder, which can be removed in a simple operation and never recur. Another type is a large growth in the bladder wall, which requires major surgery.



A large proportion of bladder cancers grow on the inside lining of the bladder. These are called **papillary** or **superficial tumours**. They look like warts or small mushrooms, with a short stem attached to the lining of the bladder. Sometimes they go on to spread into the wall of the bladder.

If bladder cancers spread into the wall of the bladder, they are called **invasive tumours**.

A few are found at a stage called **carcinoma in situ**, which is a stage just before the cancer has started to grow.

## What are the causes of cancer of the bladder?

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Some of the possible causes of cancer of the bladder are now known, but research is going on all the time to increase our understanding of the disease.

A number of factors are known to increase the risk of developing bladder cancer. Cigarette smoking is the most important factor in this country. Specific chemicals that cause bladder cancer have been found in cigarette smoke. It takes about 20 years of cigarette smoking to develop bladder cancer, and the more cigarettes smoked the greater the risk.

The other main cause of bladder cancer is exposure to certain chemicals at work, for example those used in dye factories, rubber, gasworks, plastics and other chemical industries. These chemicals were banned in the UK in 1967. However, it can take about 25 years after exposure to these chemicals before bladder cancers start to develop. If you think that you were exposed to certain chemicals through your work, do let your cancer doctor know. You may be eligible to claim industrial disease benefit from the DSS.

Frequent bouts of cystitis, caused by **repeated** bacterial infections and bladder stones, could lead to the development of bladder cancer.

In parts of the world where bilharziasis (a chronic parasitic infection of the bladder) is common, there are many cases of cancer of the bladder. This infection does not occur in the UK.

Bladder cancer occurs most commonly between 50 and 70 years of age and is twice as common in men as in women. Bladder cancer is very rare in men and women below 40 years of age.

## What are the symptoms of cancer of the bladder?

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The commonest symptom of cancer of the bladder is blood in the urine (haematuria). This usually occurs suddenly and is generally not painful. The blood may be present one day and disappear the next, but eventually it does come back. Sometimes blood clots can form, and these may cause painful muscle spasms in the bladder. The amount of blood is not related to the extent of the cancer.

Some people may have a burning feeling when they pass urine, and a need to pass urine often.

A burning sensation and the feeling of wanting to pass urine frequently are symptoms of any bladder irritation and will usually indicate an infection rather than cancer. However, if these feelings persist and do not clear with antibiotics then further tests may be necessary.

If you do see any blood in your urine, you must have it checked by your doctor as soon as possible, though this symptom is common to many conditions other than cancer, e.g. stones in the kidney or bladder.

## How does the doctor make the diagnosis?

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Usually you begin by seeing your family doctor (general practitioner) who will examine you and ask you for a urine sample. The examination should include an internal examination of the back passage (rectum) in men and an internal examination of the rectum and vagina (birth canal) in women.

The urine sample will be sent to a laboratory to be checked under a microscope for any cancer cells. Your GP may also arrange for further tests or X-rays. He or she will need to refer you to hospital for these tests, and for specialist advice and treatment.

The following tests are all used in the diagnosis of cancer of the bladder

### ***Blood tests***

Samples of your blood will be taken to check your general health, the number of cells in your blood (blood count) and to see how well your kidneys are working.

### ***Chest X-ray***

This is taken to check that your lungs and heart are healthy.

### ***Intravenous urogram (IVU or IVP)***

This test is also known as an IVU or IVP. It shows up any abnormalities in the kidneys, bladder and the rest of the urinary system. It will be done in the hospital X-ray department and takes about an hour.

A dye is injected into a vein, usually in the arm, and goes through the bloodstream to the kidneys. The doctor can watch the passage of the dye on an X-ray screen and pick up any abnormalities.

The dye will probably make you feel hot and flushed for a few minutes, but this feeling gradually disappears. You may feel some discomfort in your abdomen, but this will only be temporary. You should be able to go home as soon as the test is over.

### *Cystoscopy and biopsy*

The most important test for diagnosing cancer of the bladder is called a cystoscopy. It can be done while you are under a local or general anaesthetic.

In most cases it is done first under local anaesthetic because this is the quickest and simplest way. The test is carried out using a small, flexible, fibre-optic telescope that allows the doctor to look at the whole lining of the bladder and urethra.

If any abnormality that may be a bladder cancer is seen, the bladder has to be examined under a general anaesthetic. The doctor will then either take a small sample of the abnormality from the inside of the bladder or take samples of the lining of the bladder. This is called a **biopsy**. The samples are then examined in a laboratory under a microscope.

## Further tests

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If the tests show you do have cancer of the bladder the specialist doctor at the hospital (the urologist) will want you to have some further tests to see if the disease has spread. These tests also help the doctor to decide on the best type of treatment for you.

### *CT scan (CAT scan)*

A CT scan is another type of X-ray and is done to check the extent of any spread of the cancer. A number of pictures are taken of the pelvis and fed into a computer to form a detailed picture of the inside of the body.

You will be given a special liquid to drink a few hours before your test and again in the X-ray department. This liquid shows up on X-ray and ensures a clear picture is obtained.

Once you are lying comfortably on the couch the scan can be taken. The scan itself is painless, but it will mean you having to lie still for about 30-40 minutes.

Most people are able to go home as soon as their scan is over.

### ***Radioisotope bone scan***

A radioisotope scan may be done for some tumours, to see if any cancer cells have spread beyond the bladder and into the bones. For this test a tiny amount of a radioactive dye is injected into a vein, usually in the arm, and the patient is then scanned by a machine which measures minute amounts of radioactivity.

The doctor can tell if there has been any spread of the disease, as a larger amount of radioactivity is found in areas of bone affected by cancer cells.

After the dye has been injected you will have to wait for about an hour before having the scan, so you may want to take a magazine or book with you to pass the time.

This test does not make you radioactive as the amount of radioactivity used is so small. The radioactivity disappears from your body within a few hours.

### ***Liver ultrasound scan***

In this test sound waves are used to make up a picture of the inside of the abdomen and the liver. It will be done in the hospital scanning department.

Before your test you will be asked to drink plenty of fluids so that your bladder is full and a clear picture can be seen. Once you are lying comfortably on your back, a special gel

is spread over your abdomen. A small device, like a microphone, is passed over the area. The echoes are converted into a picture by a computer. This is a completely painless procedure and takes about 15-20 minutes.

## What types of treatment are used?

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The way that bladder cancer is treated depends on the type of cancer and how far it has spread. The first main distinction is between those cancers that are only in the lining of the bladder (**superficial**) and those which have spread into the wall of the bladder (**invasive**).

The superficial cancers, which can be single or multiple, are usually removed by a cystoscope (see Surgery, page 15). Anti-cancer (chemotherapy) drugs may be instilled into the bladder to try to prevent the cancer recurring.

### *Surgery*

Surgery is the most common form of treatment for invasive cancers. Part or all of the bladder may need to be removed. Sometimes a new bladder is constructed (see Bladder reconstruction, page 18).

### *Radiotherapy*

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

With larger tumours radiotherapy may be used before surgery to make it easier for the tumour to be removed. Radiotherapy may also be used after surgery if the surgeon feels there is a high risk of cancer cells having been left behind.

### *Chemotherapy*

In some circumstances chemotherapy is now being tried before surgery to try to shrink the tumour so that it can be operated on. Chemotherapy is also being tried after surgery to reduce the risk of the tumour coming back.

If the cancer has spread outside the bladder, the main treatment is chemotherapy.

Your doctor will discuss the best treatment with you. You may find that other patients with cancer of the bladder at the hospital are having different treatments. This may be because their illness takes a different form and therefore they have different needs. It may also be because doctors take different views about treatment.

If you have any questions about your own treatment, don't be afraid to ask your doctor or the nurse looking after you. It often helps to make a list of the questions you want to ask and to take a close relative or friend with you to remind you of the things you want to know, but can so easily forget.

Some people find it reassuring to have another medical opinion to help them decide about their treatment. Most doctors will be pleased to refer you to another specialist for a second opinion if you feel this will be helpful.

## Surgery

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### *Removal of superficial bladder tumours*

The majority of tumours in the bladder are the small papillary type (see page 9). These can usually be removed very easily using a device called a cystoscope. The tumour is simply snipped off at the stem and the area is cauterised (burned), using a mild electrical current to prevent excessive bleeding. In this way, several tumours can be treated at the same time.

After this type of treatment, follow-up cystoscopies are needed at regular intervals (usually every three to four months at first) because the tumours can often come back. Most follow-up cystoscopies can be carried out in the out-patients department under local anaesthetic. If there is any further recurrence of the cancer, the tumours can usually be surgically removed while they are still in the early stages. However, some patients at this stage may also receive chemotherapy (see page 25) or immunotherapy (see page 27), given directly into the bladder.

## *Cystectomy*

Sometimes the tumour may be too large to be removed by the cystoscope, or may have started to grow through the bladder wall. In these cases, it may be necessary to remove all or part of the bladder. If all the bladder is removed, the operation is called a **cystectomy**, and a new storage place for urine will need to be created (see Urostomy, below).

If part of the bladder is removed, the operation is called a **partial cystectomy**.

After this operation you will be able to pass urine as usual, but as your bladder will be smaller and therefore hold less urine, you will need to pass urine more frequently.

A **complete cystectomy** is the removal of the whole bladder and the creation of a new storage place for urine.

## *Urostomy*

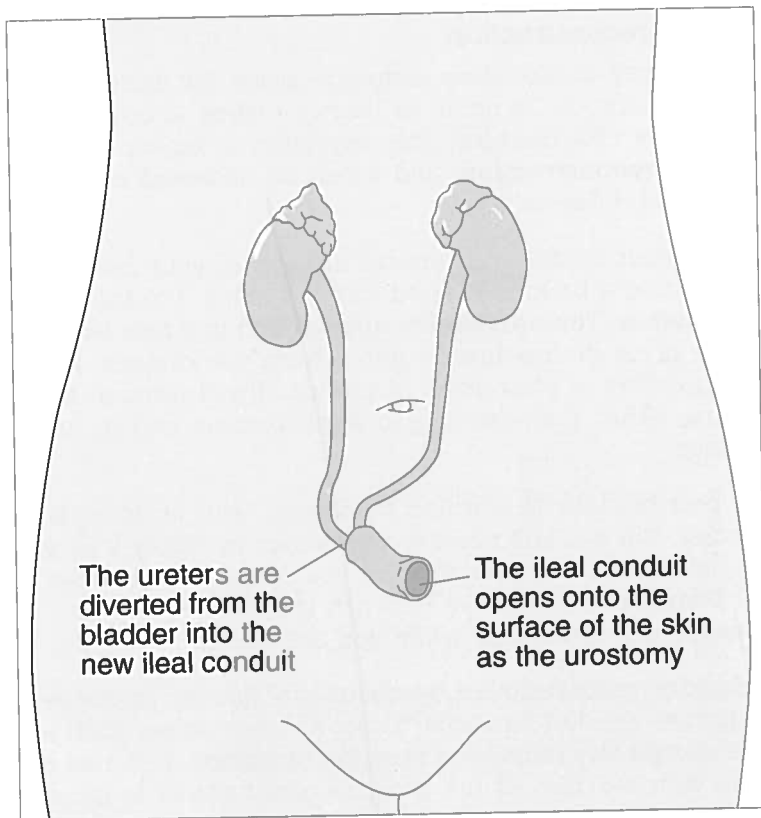
The most common way of providing a new storage place for urine is to form a **urostomy**. While you are under a general anaesthetic, the doctor will remove a segment of your small bowel, join the two ureters to one end of it and bring the other, open end out through the skin of your abdomen. This operation is called an **ileal conduit**, as the piece of small bowel (ileum) acts as a drainpipe to take the urine from the ureters and bring it to the surface of the abdomen. The bowel will be rejoined after the section to be used for the urostomy has been removed.

A flat, watertight bag is placed over the opening on the abdomen (**stoma**) to collect the urine. It is kept in place with a special type of glue. The bag will fill with urine in the same way as the bladder and will need to be emptied as necessary.

## *Continent urinary diversion*

One alternative to the ileal conduit, which has been developed in the last few years, is the **continent urinary diversion**. Urine is removed from the body through a stoma on the abdomen, in the same way as the ileal conduit.





### Urostomy

However, the main advantage of this technique is that it is not necessary to wear a stoma bag.

During an operation a pouch is formed in the abdomen, using a piece of bowel. This pouch holds the urine. A small catheter can be passed through the stoma into the pouch about 4 or 5 times a day to empty the urine. This is called **self-catheterisation**. With good teaching and practice most people cope very well with self-catheterisation and care of their stoma.

Continent urinary diversions may not be suitable for everybody, so you would need to discuss this with your own doctor.

## ***Bladder reconstruction***

Another way of providing a storage place for urine is by using a piece of the small or large intestine to construct a completely new bladder. This operation is known as **bladder reconstruction**, and it can be achieved in a number of different ways.

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

The new bladder is emptied by flexing your abdominal muscles, but you will need to remember to empty it as you will have lost the nerves that tell you when your bladder is full. Sometimes this nerve loss can lead to very slight incontinence, especially when you are asleep.

A bladder reconstruction operation will usually preserve the nerves needed for a man to get an erection so, once you have completely recovered from the operation, it should not affect your sex life. As the prostate gland needs to be removed, however, your fertility will be affected (see below).

Bladder reconstruction is not suitable for everyone.

If the cancer has started to spread beyond the bladder, the doctor can often stop further spread by removing organs close to the bladder. In women, this may mean removing the womb, ovaries and Fallopian tubes and sometimes the part of the vagina that contains the urethra. In men, the prostate gland and sometimes the urethra need to be removed. If this happens, you will be unable to have children.

This further surgery may also have an effect on your sex life and this is explained on page 20.

## Living with a urostomy

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Only a few people with cancer of the bladder will need the complete cystectomy operation that leads to having a urostomy. Most of those who do have a urostomy live a normal life. Many return to their jobs and take up their favourite pastimes again, including swimming. Learning to look after a urostomy, however, takes time and patience and no one expects you to cope straightaway. Like anything new, it will get better with practice.

Most hospitals have specially trained nurses called stoma care nurses, who will show you how to look after your urostomy and help you cope with any problems. You may also find it helpful to talk with someone who has already learned to live with a urostomy. Your nurse or doctor can often arrange for a volunteer to visit you and talk to you about the more personal aspects. This advice, which comes from their own experience, can be invaluable, especially in the first few months after your operation.

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

For the first few days after your operation, the nurse will look after your urostomy for you and make sure that the bag is emptied and changed as often as is necessary. At first your stoma will be slightly swollen and it may be several weeks before it settles down to its normal size. The stoma may also produce mucus (a thick white substance). As time passes the amount of mucus produced will gradually lessen, but will never disappear completely.

As soon as you feel ready the nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to join you at this time in case you ever need help at home. There are several different types of bag or appliance available and the nurse will help you to choose one that suits you best. When you are changing your bag, it helps to allow yourself plenty of time and privacy, so that you can work at your own pace without interruptions.

Before you leave hospital, the nurse will make sure you have a good supply of urostomy bags. When you are at home, you can get all your supplies from your chemist. As some chemists do not have a very large stock it is often a good idea to place your order well in advance. Sometimes it is better to get your supplies direct from a local stockist. The Urostomy Association (see page 44) can give you details of these.

Once you are at home you will still be able to phone your stoma care nurse for advice. Your GP may also be able to arrange for a district nurse to visit you for a few days when you first leave hospital, to sort out any problems you may have with your urostomy.

## **Will the operation affect my sex life?**

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

You may also be very concerned about the effect it may have on your personal relationships and lifestyle. You may be worried about rejection, continuing to have sex with your partner, or starting a new relationship. Many people find that once they have summoned up the courage to talk

about their fears with a partner, their minds are set at ease. Just expressing your feelings can help to clarify your fears and also gives others the opportunity to understand how you are feeling. Fears of rejection are usually unfounded. Intimate relationships are built on love and trust. New partners can be understanding and supportive if you are open and honest about your misgivings from the start.

Most modern appliances are designed to be flat and unnoticeable under clothing, but the size and site of the stoma will be the most important factor in whether or not the bag or appliance is noticeable through your clothes. The style of clothing you wear is obviously important, but many young people with a urostomy find that they can wear the tightest clothes without advertising that they are wearing a bag. Although you may remain conscious of your urostomy, few other people will ever notice unless you tell them.

Apart from the psychological adjustments, the operation may have made physical changes which can cause problems with sex. It is often impossible to avoid damage to the nerves in the pelvis during the operation, although your doctor will do all he or she can to prevent nerve damage. If this has happened it may be difficult for a man to get an erection. However, it is now possible for men who have problems getting erections to be treated with injections into the penis of a drug called prostaglandin E1 (Caverject).

There are two alternatives to prostaglandin. One is the use of mechanical devices to produce an erection. These are called penile prostheses and involve the insertion, under general anaesthetic, of flexible rods or thin inflatable cylinders into the penis. Your doctor will be able to give you advice about both these treatments, which may be available from the National Health Service.

The other is the use of external vacuum devices to produce erections. They are simple, painless and easy to use, and are available from sex aid shops or on prescription (although they are not usually available through the NHS).

You may find it difficult or embarrassing to talk about any sexual problems you may have. However, most doctors are very understanding, and even if they are unable to help they can refer you to a doctor or therapist who specialises in sexual problems. These specialists can offer emotional support and advice on how to cope with impotence and any related problems. It can be helpful to remember that they deal with situations like this every day and are used to discussing personal problems. If you have a partner, it may be helpful for him or her to see the specialist with you so that any fears and worries can be brought out into the open. (See pages 42-44 for some useful organisations you can contact without a referral from your doctor).

In some women, the vagina (birth canal) may have been shortened or narrowed during the operation to remove the bladder, although the doctor will take care to leave as much of the vagina intact as possible.

This can make sex difficult or uncomfortable at first. One of the best ways of overcoming this problem is to start having sex regularly and gently, as soon as you feel ready. This will gradually stretch the vagina, making it more supple, and will make sex easier and more enjoyable.

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

One common fear is that cancer cells can be passed on to your partner during sex. This is not true. Cancer is not infectious and it is perfectly safe for you to have sex as soon as you feel ready. CancerBACUP can also provide a booklet called *Sexuality and cancer*, which you may find helpful.

# Radiotherapy

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Radiotherapy treats cancer by using high energy rays which destroy the cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is often given as an alternative to surgery, which might then only be necessary if a recurrence of the cancer is found later on. It is also sometimes given before surgery to reduce the risk of cancer cells being left in the pelvis after the operation. It may be given after the operation if the surgeon is concerned that there is a high risk of cancer cells having been left behind.

## ***External radiotherapy***

The treatment is given in the hospital radiotherapy department. The course is usually in five sessions from Monday to Friday, with a rest at the weekend. The length of your treatment will depend on the type and size of the cancer. Your doctor will discuss the treatment with you.

## ***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 will be asked to lie under a machine called a CT scanner which takes X-rays of the area to be treated. Sometimes a machine called a simulator can be used for the same purpose. Treatment planning is a very important part of radiotherapy and it may take a few visits before the radiotherapist, the doctor who plans your treatment, is satisfied with the result.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where the rays are to be directed. These marks must remain visible throughout your treatment but they can be washed off once your treatment is over. At the beginning of your treatment you will be given instructions on how to look after the skin in the area being treated.

Sometimes a few permanent tattoo marks are made on your skin instead of pen marks. These marks are tiny, and will only be done with your permission.

Before each session of radiotherapy the radiographer will position you carefully on the couch and make sure 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 radiographer who will be watching you from an adjoining room. Radiotherapy is not painful but you do have to lie still for a few minutes while your treatment is being given.

### ***Side effects***

Radiotherapy to the pelvis may irritate the bowel and cause diarrhoea and soreness around the anus. It may also cause mild cystitis, and make you pass urine more often or experience a burning feeling when you pass urine.

In a small number of cases, the bowel or bladder may be permanently affected by the radiotherapy. If this happens then increased bowel motions and diarrhoea may continue.

Radiotherapy can also cause general side effects such as nausea, vomiting, diarrhoea and tiredness. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. The radiotherapist will be able to advise you what to expect.

Nausea can usually be effectively treated by anti-emetics (anti-sickness drugs) which your doctor can prescribe. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks which are available from most chemists and can be prescribed by your GP. CancerBACUP's booklet *Diet and the cancer patient* has some helpful hints on how to eat well when you are ill.

Although radiotherapy for some cancers can cause hair loss, this only occurs in the area being treated. For example, if you have radiotherapy to the pelvis you may lose some of your pubic hair. When you have finished the



course of treatment, the hair will often grow back. However, the regrowth may be thinner or finer than it was before.

As radiotherapy can make you tired, try to get as much rest as you can, especially if you have to travel a long way for treatment each day.

All these side effects will disappear gradually once your course of treatment is over, but it is important to let your doctor know if they do continue.

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

CancerBACUP publishes a booklet called *Understanding radiotherapy*, which gives more details about this treatment and its side effects.

## Chemotherapy

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

Chemotherapy given directly into the bladder is called **intravesical** chemotherapy. The drugs are injected into the bladder through a catheter. Giving chemotherapy in this way puts the drugs in direct contact with the tumour and the lining of the bladder. It also reduces any side effects, as very little gets into the bloodstream to affect the rest of the body. The drugs may be given as one injection, or a course of weekly injections for about six weeks.

If the cancer has spread into the muscle of the bladder, or to other parts of the body, the chemotherapy drugs are given **intravenously**. This is done so that they can circulate

in the bloodstream and reach the cancer cells all over the body. A course of several drugs is given over a few days. The course is then repeated every few weeks for several months.

Intravenous chemotherapy may be given before surgery to shrink the cancer and make it easier to operate; after surgery if it is thought there is a high risk of the cancer coming back; or if the cancer has already spread to other parts of the body.

### ***Side effects***

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

If you receive chemotherapy intravenously, the drugs reduce temporarily the number of normal cells in your blood. When these cells are in short supply, you are more likely to get an infection and to tire easily. It is important to let your doctor know straight away if you feel unwell or develop a temperature at any time during your treatment. During chemotherapy your blood will be tested regularly and, if necessary, you will be given blood transfusions or antibiotics to treat any infection.

Some of the drugs which may be used can cause nausea and vomiting. This can often be helped by taking anti-sickness drugs (anti-emetics) which your doctor can prescribe.

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

If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet. CancerBACUP's booklet *Diet and the cancer patient* has some useful tips on coping with eating problems.

Hair loss is another common side effect of these drugs. People who lose their hair often wear wigs, hats or scarves.

You may be entitled to a free wig from the National Health Service. Your doctor or the nurse looking after you will be able to arrange for a wig specialist to visit you. If you do lose your hair it should grow back within about six months. CancerBACUP has a booklet called *Coping with hair loss* which we would be happy to send you.

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

Chemotherapy affects people in different ways. Some find they are able to lead a fairly normal life during their treatment, but many find they 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.

CancerBACUP's booklet *Understanding chemotherapy* discusses the treatment and its side effects in more detail. We would be pleased to send you a copy. Factsheets about individual drugs and their particular side effects are also available.

## Immunotherapy

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Immunotherapy uses the body's immune system to combat the cancer cells.

An insertion of a vaccine called BCG (the vaccine used for tuberculosis) into the bladder has been shown to be an effective treatment for superficial bladder cancers.

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

The treatment takes place in the urology out-patients department. It is given once a week, for six weeks. The vaccine is instilled directly into the bladder through a catheter. You should not pass urine for two hours

afterwards, as it is during this time that the treatment is working. For the next six hours, when you do pass urine, you should sit rather than stand (men as well as women) to avoid splashing.

During the treatment you may experience troublesome symptoms, such as:

blood in your urine; fever and chills; needing to pass urine often; pain in your joints; nausea and vomiting; pain when you pass urine; cough; skin rash; severe tiredness.

Many of these symptoms are to be expected and they almost always settle down on their own. You should however tell your doctor about them when you next see him/her.

It is important to let your doctor know about any other drugs you are taking, because if you are taking other drugs that suppress your immune system, they may interfere with how well your bladder cancer responds to this treatment.

The treatment may be repeated at intervals over the next two years. Your doctor will arrange this with you if it is necessary in your case.

## New treatments

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### *Photodynamic therapy*

This is a new treatment, and its value is still being assessed.

A light-sensitive drug is injected intravenously, and the bladder is filled with a salt solution. A laser is then shone into the bladder. This activates the drug, which destroys the cancer cells.

The main side effect of this treatment is that it makes the patient very sensitive to sunlight.

## Follow up

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

## Research – clinical trials

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Research into new ways of treating cancer of the bladder is going on all the time. As no current cancer treatment results in the cure of all the patients treated, cancer doctors are continually looking for new ways to treat the disease and they do this by using clinical trials. Many hospitals now take part in these trials. CancerBACUP holds a list of some current trials and can put you in touch with the appropriate organisation or doctor.

If early work suggests that a new treatment might be better than the standard treatment, cancer doctors will carry out trials to compare the new treatment with the best available standard ones. This is called a controlled clinical trial and is the only reliable way of testing a new treatment.

Often several hospitals around the country take part in these trials.

So that the treatments can be compared accurately, the type of treatment a patient receives is decided at random – typically, by a computer – and not by the doctor treating the patient. This is because it has been shown that if a doctor chooses the treatment, or offers a choice to the patient, he or she may unintentionally bias the result of the trial.

In a randomised controlled clinical trial, some patients will receive the best standard treatment while others will receive the new treatment, which may or may not prove to be better than the standard treatment. A treatment is better either because it is more effective against the tumour or because it is equally effective and has fewer unpleasant side effects.

The reason why your doctor would like you to take part in a trial (or study as they are sometimes called) is because until the new treatment has been tested scientifically in this way it is impossible for doctors to know which is the best one to choose for their patients.

Before any trial is allowed to take place it must have been approved by an ethics committee. Your doctor must have your informed consent before entering you into any clinical trial. Informed consent means that you know what the trial is about, you understand why it is being conducted and why you have been invited to take part, and you appreciate exactly how you will be involved.

Even after agreeing to take part in a trial, you can still withdraw at any stage if you change your mind. Your decision will in no way affect your doctor's attitude towards you. If you choose not to take part or you withdraw from a trial, you will then receive the best standard treatment rather than the new one with which it is being compared.

If you do choose to take part in a trial, it is important to remember that whatever treatment you receive will have been carefully researched in preliminary studies, before it is fully tested in any randomised controlled clinical trial. By taking part in a trial you will also be helping to advance medical science and so improve prospects for patients in the future.

CancerBACUP has a booklet called *Understanding clinical trials*, which explains clinical trials in more detail. We would be happy to send you a copy.

## Your feelings

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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.

### ***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 their illness with their family and friends. Others may feel an overwhelming urge to discuss it with those around them. This may be a way of helping them to accept the news themselves.

CancerBACUP has a booklet called *Who can ever understand? – talking about your cancer*, which we would be happy to send to you.

### ***Fear and uncertainty***

*'Am I going to die?'; 'Will I be in pain?'*

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

In fact, nowadays many cancers are curable if caught at an early enough stage. When a 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.

Many people feel they need to sort out their affairs when they have been diagnosed with cancer, or any other potentially life-threatening illness. Doing so can take away some of that uncertainty, and reassure them that whatever happens their family will be looked after. One way to do this is to make a will, and CancerBACUP has a booklet, *Will power*, which can help.

'Will I be in pain?' and 'Will any pain be unbearable?' are other common fears. In fact, many people with cancer feel no pain at all. For those who do, there are many modern drugs and other techniques which are very successful at relieving pain or keeping it under control. Other ways of easing pain or preventing you from feeling pain are radiotherapy and nerve blocks. CancerBACUP has a booklet called *Feeling better – controlling pain and other symptoms of cancer* which may help you understand more about these procedures. We will be happy to send this to you.

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 you may want to ask (see fill-in form at the end of this booklet). If you don't understand something about your treatment – ask. 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. You may want them to ask some of the questions you yourself might be hesitant of putting to the doctor.

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 can't answer your questions fully, or that their answers may sound vague. It is often impossible to say for certain that they have completely removed the tumour. Doctors know from past experience approximately how many people will benefit from a certain



treatment, but it is impossible to predict the future for a particular person. 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. Gaining some knowledge about your illness can be reassuring. Discussing what you have found out with your family and friends can help to relieve tension caused by unnecessary worry.

### ***Denial***

*'There's nothing really wrong with me'; 'I haven't got cancer'*

Many people cope with their illness by not wanting to know anything about it, or not wanting to talk about it. If that's the way you feel, then just say quite firmly to the people around you that you would 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. Start perhaps by reassuring 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 of all people?'; 'And why right now?'*

Anger can hide other feelings such as fear or sadness and you may vent your anger 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 there's no need to feel guilty about your angry thoughts or irritable moods. However, relatives and friends 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, or if you would find that difficult, perhaps you could show them this section 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. CancerBACUP can give you details of how to get this sort of help in your area.

### ***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 why it should have happened to them. This may be because we often feel better if we know why something has happened, but since doctors rarely know exactly what has caused an individual's cancer, there's no reason for you to blame yourself.

### ***Resentment***

*'It's all right for you, you haven't 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.

**Don't bottle up your feelings**

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. It will make it easier for them to cope, however, if 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.

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 or counsellor who specialises in the emotional problems of people with cancer.

## ***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.

Although the treatment for cancer of the bladder can cause unpleasant side effects, many people do manage to lead an almost normal life during their treatment. Obviously you will need to take time off for it, and some time afterwards to recover. Just do as much as you feel like and try to get plenty of rest.

**Everyone needs some support during difficult times**

It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling they can be more supportive.

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

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Some families find it difficult to talk about cancer or share their feelings. It may seem best to pretend that everything is fine, and carry on as normal, perhaps because you don't want to worry the person with cancer or feel you are letting him or her down if you admit to being afraid. Unfortunately, denying strong emotions like this can make it even harder to talk, and lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what and how much the person with cancer wants to say. Don't rush into talking about the illness. Often it is enough just to listen and let the person with cancer talk when she or he is ready.

CancerBACUP has a booklet, *Lost for words*, written for relatives and friends of people with cancer. It looks at some of the difficulties people may have when talking about cancer, and suggests ways of overcoming them.

## Talking to children

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Deciding what to tell your children about your 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 usually need only simple explanations of why their relative or friend has had to go into hospital or isn't his or her normal self. Slightly older children may understand a story explanation in terms of good cells and bad cells. All children need to be repeatedly reassured that your 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.

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 your illness. Even very young children can sense when something is wrong, so don't 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.

**CancerBACUP has a booklet called *What do I tell the children? – a guide for a parent with cancer, which we would be happy to send you***

## What you can do

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Many people feel helpless when they are first told they have cancer. They think there is nothing they can do, other than hand themselves over to 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 to prevent it causing 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 you go to see the doctor or nurse, or take a friend or relative with you to remind you of things you want to know but can forget so easily. Other sources of information are given at the end of this booklet, along with a fill-in form to note your questions before your visit.

### ***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 can help some people 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 which you can practise at home with audiotapes. CancerBACUP has booklets called *Cancer and complementary therapies* and *Diet and the cancer patient*, which we would be happy to send to you.

Some people find that their experience of cancer has taught them to prioritise their time and use their energy more constructively than they did before their illness.

You may 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 then do not feel you have to do these things; just do whatever suits you. Some people may 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.

## Who can help?

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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 listen.

The Cancer Support Service can tell you more about counselling and can let you know what services are available in your area (see page 41). Some people find great comfort in religion at this time and it may help for them to talk to a local minister, hospital chaplain or other religious leader.

There are several other people who can offer support in the community. District nurses work closely with GPs and make regular visits to some patients and their families at home. In many areas of the country there are also Macmillan and Marie Curie nurses, who are specially trained to look after people with cancer in their own homes. Let your GP know if you are having any problems so that proper home care can be arranged.

Some hospitals have their own emotional support services with specially trained staff and some of the nurses on the ward will have been given training in counselling as well as being able to give advice about practical problems. The hospital social worker is also often able to help in many ways such as giving information about social services and other benefits you may be able to claim while you are ill. For example, you may be entitled to meals on wheels, a home help or hospital fares. The social worker may also be able to help arrange childcare during and after treatment and, if necessary, help with the cost of childminders.

But there are people who require more than advice and support. They may find that the impact of cancer leads to depression, feelings of helplessness and anxiety. Specialist help in coping with these emotions is available in some hospitals. Ask your hospital consultant or GP to refer you to a doctor or counsellor who is an expert in the special emotional problems of cancer patients and their relatives.

## ***Sick pay and benefits***

Incapacity Benefit has replaced Invalidity Benefit and Sickness Benefit. There are three rates of Incapacity Benefit: a short-term lower rate, a short-term higher rate, and a long-term rate.

If you are employed and unable to work, your employer can pay you Statutory Sick Pay (SSP) for a maximum of 28 weeks. If, after this period, you are still unable to work, you can claim the short-term higher rate of benefit from the Benefits Agency. After one year, if you are still unable to work, you can claim long-term Incapacity Benefit.

If you are self-employed, you are entitled to the same benefits as long as you have been paying the relevant Class 2 contributions.

People who are unemployed and unable to work will need to transfer from the Job Seekers Allowance to the short-term lower rate of Incapacity Benefit.

If you are ill and not at work, do remember to ask your family doctor for a medical certificate to cover the period of your illness. If you are in hospital, ask the doctor or nurse for a certificate, which you will need to claim benefit. You may also be required to take a medical test to assess whether or not you are eligible for benefit.

You may qualify for the Disability Living Allowance. Ask your family doctor for form DS1500.

The Benefits Agency has a form (IB202) which outlines all these benefits and others to which you may be entitled. You can get a copy from your local Citizens' Advice Bureau and Social Security office, who will also be able to advise you about the benefits you can claim. Their addresses and telephone numbers are in the phone book.



# CancerBACUP's services

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## *Cancer Support Service*

Provides information on all aspects of cancer and its treatment, and on the practical and emotional problems of living with the illness. The cancer information specialist nurses can give information about services available to cancer patients, treatment and research centres, support groups, therapists, counsellors, financial assistance, insurance, mortgages, home nursing services and much more. Some of these are listed on the following pages.

The emotional difficulties linked to cancer are not always easy to talk about and are often hardest to share with those to whom you are closest. Talking with a trained counsellor who is not personally involved can help to untangle thoughts, feelings and ideas. The support service can give information about local counselling services and can discuss with people whether counselling could be appropriate and helpful for them.

You can phone and speak to one of our experienced cancer nurses. The Cancer Support Service is open to telephone enquiries from 9am to 7pm Monday to Friday. The numbers are: 0171 613 2121 (from 22 April 2000, 020 7613 2121) or Freephone 0808 800 1234 (this number is not due to change).

## *Booklets*

For a list of CancerBACUP booklets, or to order another CancerBACUP booklet, phone 0171 696 9003 (from 22 April 2000, 020 7696 9003).

## *Website*

CancerBACUP information is available on our website: [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk), and on a CD-ROM – for details, phone 0171 696 9003 (from 22 April 2000, 020 7696 9003).

## Useful organisations

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### **CancerBACUP**

3 Bath Place  
Rivington Street  
London  
EC2A 3DR  
Office: 0171 696 9003  
(from 22 April 2000, 020 7696 9003)

### **CancerBACUP Scotland**

30 Bell Street  
Glasgow  
G1 1LG  
Office: 0141 553 1553

### **Cancer Support Service**

0171 613 2121 (from 22 April 2000, 020 7613 2121)  
Freephone 0808 800 1234  
Open 9am - 7pm Monday-Friday  
For those with hearing difficulties, all CancerBACUP's  
London numbers can take minicom calls.

Note: London phone numbers are changing. From 22 April 2000, you should replace the prefix 0171 with 020 7. The national number for ordering booklets, for example, will change from 0171 696 9003 to 020 7696 9003. For calls from **inside** the current 0171 area, a 7 will have to be added to the seven-digit number – for example, the booklet ordering number will change from 696 9003 to 7696 9003.

### **CancerBACUP Nottingham**

Nottingham City Hospital, Hucknall Road, Nottingham NG5  
1PB  
Admin: 0115 840 2650

### **CancerBACUP Jersey**

6 Royal Crescent, St Helier, Jersey JE2 4QG  
Tel: 01534 89904 Freephone: 0800 735 0275

*In addition to providing a link with CancerBACUP's Cancer Support Service in the Channel Islands, CancerBACUP Jersey runs a local cancer support group and trained local volunteers give support over the telephone, and in the local hospital.*

CancerLink  
11-21 Northdown Street  
London N1 9BN  
Tel: 0171 833 2818  
0800 132905 (Freephone helpline)  
0800 590415 (Asian language helpline)

*Offers support and information on all aspects of cancer in response to telephone and letter enquiries. Acts as a resource to cancer support and self-help groups throughout the UK, and produces a range of publications on issues about cancer.*

Cancer Care Society  
21 Zetland Road, Redland, Bristol BS6 7AH  
Tel: 0117 942 7419

*Provides counselling and emotional support where possible through a network of support groups around the country. Holiday accommodation is available, and in some areas hospital visiting and help with transport.*

Macmillan Cancer Relief  
Anchor House, 15-19 Britten Street, London SW3 3TZ  
Tel: 0171 351 7811  
(With regional offices throughout the country)

*Provides specialist advice and support through Macmillan nurses and doctors, and financial grants for people with cancer and their families.*

The Continence Advisory Service  
Continence Foundation  
Tel: 0191 213 0050 (helpline)

*Advice available in 10 languages on urinary and faecal incontinence and related bowel and bladder problems. Acts as an umbrella group for more specialised organisations.*

Marie Curie Cancer Care  
28 Belgrave Square, London SW1X 8QG  
Tel: 0171 235 3325

*Runs eleven hospice centres for cancer patients throughout the UK, and a community nursing service which works in conjunction with the district nursing service to support cancer patients and their carers in their homes.*

Tak Tent Cancer Support – Scotland  
Block C20, Western Court  
100 University Place, Glasgow G12 6SQ  
Tel: 0141 211 1932 (helpline/information)

*Offers information, support, education and care for cancer patients, families, friends and professionals. Network of support groups throughout Scotland. 'Drop-in' Resource and Information Centre at the above address.*

Tenovus Cancer Information Centre  
PO Box 88, College Buildings, Courtenay Road, Splott,  
Cardiff CF1 1SA  
Tel: 0800 526527 (freephone helpline)  
01222 497700 (admin)

*Provides an information service in English and Welsh on all aspects of cancer, and emotional support for cancer patients and their families. Operates a mobile screening unit, drop-in centre, support group and cancer helpline.*

The Ulster Cancer Foundation  
40-42 Eglantine Avenue, Belfast BT9 6DX  
Tel: 01232 663439 (helpline)  
01232 663281 (admin)

*Provides a cancer information helpline and resource centre, and support groups for patients and relatives. Produces a range of booklets.*

The Urostomy Association  
Buckland, Beaumont Park, Danbury, Essex CM3 4DE  
Tel: 01245 224294

*An association of 26 groups throughout the country offering mutual support and counselling. They will arrange visits before and after surgery.*

## Books recommended by CancerBACUP

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*Cancer: a positive approach*

Hilary Thomas and Karol Sikora  
Thorsons, 1995  
ISBN 0-7225-3132-X £8.99

Information about all aspects of cancer and the treatments available. Also looks at the controversies in cancer, and includes checklists of questions to ask your doctor.

*Cancer: the facts*

Michael Whitehouse and Maurice Slevin  
Oxford University Press, 1996  
ISBN 0-1926-1695-1 £8.99

Information on diagnosis and treatment of different types of cancer. Also considers the emotional needs of cancer patients, living with advanced cancer, and the role of complementary medicine.

*Cancer: what every patient needs to know*

Jeffrey Tobias  
Bloomsbury, 1995  
ISBN 0-7475-1993-5 £6.99

Thorough and up-to-date coverage by a respected cancer doctor.

*Cancer information at your fingertips: the comprehensive cancer reference book for the 1990s (2nd edn)*

Val Speechley and Maxine Rosenfield  
Class Publishing, 1996  
ISBN 1-872362-56-7 £11.95

Questions and answers about cancer, its diagnosis, treatment, side effects, complementary therapies and life with cancer.

*Challenging cancer: from chaos to control*

Nira Kfir and Maurice Slevin

Tavistock/Routledge, 1991

ISBN 0-415-06344-2 £50

For people who have been diagnosed with cancer, their families and friends. Examines feelings and emotions with the help of a psychotherapist and a cancer doctor. Suggests ways people can regain control of their lives.

*What you really need to know about cancer: a comprehensive guide for patients and their families*

Robert Buckman

Macmillan, 1996

ISBN 0-333-6186-6 £20

Chapters on all types of cancer. Very comprehensive coverage, including sections on conventional and complementary treatments, screening, living with cancer and attitudes to cancer.

# CancerBACUP publications

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## ***Understanding cancer series:***

|                               |                        |
|-------------------------------|------------------------|
| Acute lymphoblastic leukaemia | Lung                   |
| Acute myeloblastic leukaemia  | Lymphoedema            |
| Bladder                       | Malignant melanoma     |
| Bone cancer – primary         | Mouth and throat       |
| Bone cancer – secondary       | Myeloma                |
| Brain tumours                 | Non-Hodgkin's lymphoma |
| Breast – primary              | Oesophagus             |
| Breast – secondary            | Ovary                  |
| Cervical smears               | Pancreas               |
| Cervix                        | Prostate               |
| Chronic lymphocytic leukaemia | Skin                   |
| Chronic myeloid leukaemia     | Soft tissue sarcomas   |
| Colon and rectum              | Stomach                |
| Hodgkin's disease             | Testes                 |
| Kaposi's sarcoma              | Thyroid                |
| Kidney                        | Uterus                 |
| Larynx                        | Vulva                  |
| Liver                         |                        |

## ***Understanding treatment series:***

|                       |  |
|-----------------------|--|
| Breast Reconstruction | The Big Lung Trial                       |
| Chemotherapy          | Radiotherapy                             |
| Clinical trials       | Stem cell and bone marrow<br>transplants |

**Factsheets on many individual drug treatments for cancer are also available**

## ***Living with cancer series:***

|  |   |
|--|---|
| Complementary therapies<br>and cancer                            | Lost for words: how to talk to<br>someone with cancer               |
| Coping at home: caring for<br>someone with advanced cancer       | Sexuality and cancer  |
| Coping with hair loss  | What do I tell the children? A<br>guide for a parent with cancer    |
| Diet and the cancer patient                                      | What now? Adjusting to life after<br>cancer                         |
| Facing the challenge of<br>advanced cancer                       | Who can ever understand?  |
| Feeling better: controlling pain<br>and other symptoms of cancer | Talking about your cancer   |
|  | Will power: a step-by-step guide<br>to making or changing your will |

***Questions you might like to ask your doctor or surgeon***

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. ....

Answer .....

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2. ....

Answer .....

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3. ....

Answer .....

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4. ....

Answer .....

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5. ....

Answer .....

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6. ....

Answer .....

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