

COLORECTAL CANCER
ITS INVESTIGATION AND TREATMENT

A patient information document for patients of:

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I expect you to make a rapid recovery after your operation and to experience no serious problems. However, it is important that you should know about minor problems which are common after this operation and also about more serious problems which can just occasionally occur. The sections of this booklet headed "What Problems Can Occur After the Operation?" describe these and I would particularly ask you to read them.

What is Bowel Cancer?

Bowel cancer is an abnormal growth of cells in the lining of the large bowel. As a result of a long and complex series of changes, these abnormal cells become cancerous. A malignant tumour consists of cancer cells that have the ability to spread beyond the original site and, if left untreated, may invade and destroy surrounding tissues. Sometimes cells break away from the original primary cancer and spread to other sites in the body via the blood stream or lymphatic system. These cells may then go on to develop secondary tumours or metastases.

How Common is Bowel Cancer?

Bowel cancer is the second commonest cause of cancer death in the United Kingdom. It affects both men and women. Approximately 30,000 new cases are diagnosed each year. The disease is curable when not too far advanced.

What Causes Cancer of the Large Bowel?

In most people the cause of cancer of the large bowel is still unknown. However, your risk of bowel cancer is increased if any of the following apply:-

- If you have a tendency to develop polyps or have a family history of polyps, bowel cancer or other forms of cancer (particularly the digestive tract).

- If you are in the late middle to old age group.
- If you have inflammatory bowel disease eg ulcerative colitis for over ten years.
- If you eat a diet containing low levels of fibre, high levels of fat and excess alcohol.
- If you are severely overweight and lead a sedentary lifestyle.

Is Bowel Cancer Hereditary?

Yes, in so far as people can inherit a tendency to develop bowel cancer, but many people who suffer from it have no history of the disease. There are two genetic syndromes that lead to a cancer developing at a relatively early age: hereditary non-polyposis colorectal cancer (HNPCC) and familial adenomatous polyposis (FAP).

In addition to these rare genetic syndromes, close relatives of people diagnosed with colorectal cancer are at an increased risk. The risk is greater the larger the number of relatives affected, the closer the family relationship and the younger they are at the time of diagnosis. However, bowel cancer is so common that 10% of people over the age of 50 will have an affected relative. People with a single relative diagnosed with bowel cancer over the age of 60 have the same risk as the general population. Almost a quarter of patients with colorectal cancer have a positive family history.

What are the Warning Signs of Bowel Cancer?

Any of the following persisting for two weeks or more:

Diarrhoea

Constipation

Blood or mucus in your stools

Unexplained anaemia

Abdominal pain

Unexplained weight loss

Abdominal fullness

Feeling of incomplete emptying of the bowel

Severe wind or "wet wind"

How do we make the Diagnosis?

In cases of suspected colorectal cancer the large bowel is examined by one of two methods, colonoscopy or sigmoidoscopy, plus double contrast barium enema. In colonoscopy a flexible, tubular, narrow telescope is inserted into the anus whilst you are sedated and threaded along the whole of the large bowel.

In sigmoidoscopy a short, lighted telescope is passed through the back passage into the rectum to inspect the lining (mucosa) of the bowel. The diagnosis will be confirmed by painlessly removing small samples of the cells (biopsy).

A barium enema involves passing a narrow tube through the anus through which some liquid barium is passed. This barium coats the lining of the bowel that can be visualised by taking a series of x-rays. In order to examine the whole of the bowel the radiographer will take x-rays of you in different positions. In order to perform colonoscopy and barium enema examination, it is important that you go on to a low residue diet and take a liquid purgative to clean the bowel.

Pre-operative Staging

Unless the findings are unlikely to influence further management of your cancer, Mr Dixon will arrange for some additional investigations to be performed in the hospital X-ray Department. These tests may detect if there has been any spread of the disease and helps me to decide on the best type of treatment for each individual.

Ultrasound Scan

In this test sound waves are used to look at the texture of your liver. The echoes are converted into a picture using a computer. It is a painless test and only takes a few minutes. If you have not had this

examination before your operation, Mr Dixon, or a member of his team, will perform the investigation at the time of surgery. An ultrasound scan of the liver will only correctly identify approximately 60% of patients whose cancer has spread to the liver.

CT Scan

A CT scan is a type of x-ray whereby a number of pictures are taken of the area and fed into a computer to form a detailed picture of the inside of your body. Mr Dixon requests this test in patients whose cancer is sited within the rectum. This test is particularly useful in helping us decide whether or not you ought to receive other treatments prior to surgery, for example radiotherapy. The scan is also more accurate ($\frac{2}{3}$ of patients) in detecting any spread of the cancer to the liver. We will aim to perform the scan within seven working days of asking.

On the day of the scan you will be asked to fast for at least four hours and will be given a special liquid to drink which shows up on the x-ray. A similar liquid may be placed into your back passage through a small tube just before the scan. The scan is painless but you do need to lie still for about thirty minutes. Most people will go home as soon as the scan is over. In addition, Mr Dixon will make arrangements for you to have a chest x-ray and blood tests. We will make arrangements to see you in the next clinic to discuss the results of your tests and the type of treatments that are available. Obviously, this waiting period will be an anxious time for you and it may help to talk things over with a close friend/relative or our Specialist Colorectal Cancer Nurse, Sister Lesley Atkins. Sister Atkins will aim to make personal contact. If she is unavailable we will give you a contact number.

What Types of Treatment are Used?

Surgery is the main treatment for cancer of the large bowel. About 80% of patients undergo surgery with the hope of being cured. Unfortunately, a proportion of them will not survive more than five years. Because of this, you will be considered for additional treatment such as radiotherapy and chemotherapy. Mr Dixon will plan your treatment by taking into consideration a number of factors, including your age, general health, the type, size and position of the tumour, the depth the tumour has invaded the wall of the bowel, what it looks like under the microscope and whether it has spread beyond the bowel.

You may find that other people at the hospital are having different treatment from yourself. This is because illnesses can take different forms and therefore have different needs. It may also be because doctors take different views about treatment. Mr Dixon will discuss your individual case with other consultant members of the multi-disciplinary team, these include Dr Hopkins and Dr Falk, Consultant Clinical Oncologist/Radiotherapists, Dr Rigby, Consultant Histopathologist, and Drs Slack and Longstaff, Consultant Radiologists. If you have any questions about your own treatment, do not be afraid to ask us. It often helps to make a list of questions and to bring a close friend or relative with you when you see Mr Dixon. Some people find it reassuring to have another medical opinion to help them decide about their treatment. Mr Dixon will be pleased to refer you to another specialist for a second opinion if you feel that this will be helpful.

Surgery

Long term survival is only likely when the tumour has been completely removed. In many ways, the long term survival is outside Mr Dixon's control, being dependent on the presence or absence of occult liver metastases (microscopic spread to the liver) at the time of presentation. The surgeon can, however, control the following:

- (i) Death in hospital (<2%).
- (ii) Local (pelvic) recurrence of the cancer (6%).

- (iii) Quality of life
 - avoid a stoma (colostomy).
 - preservation of sexual and urinary functions.

Before any operation, Mr Dixon and his team will make sure that you have fully discussed the ins and outs and remember, no operation or procedure will be done without your consent. Surgery is the most common form of treatment for cancer of the colon (large bowel). Usually the piece of colon that contains the cancer is removed and the two open ends are then joined together using an absorbable suture. During the operation Mr Dixon's team will remove the nearby lymph nodes, as these are the first place to which the cancer may spread.

In patients who have cancer of the rectum, Mr Dixon employs the technique of total mesorectal excision (TME) in which meticulous care is taken to remove all the tissue that surrounds the tumour. Some studies suggest that this technique greatly reduces recurrence rates (5-8%) and improves overall survival (75% 5 year survival). The major advantage of this technique is that it can preserve the anal sphincter. This avoids the need for a stoma (a new opening of the bowel - colostomy - at the surface of the abdomen for the passage of bowel contents). A bag is worn over the stoma to collect the stool. If you have received a pre-operative course of radiotherapy, healing of the bowel join can be impaired and to reduce the risks of any problems arising, Mr Dixon will temporarily create a stoma that can be closed a few months later at a further operation. When the tumour is very low in the rectum there may be no alternative to removing the whole of the rectum and sphincter (Abdominoperineal excision of rectum APER) which necessitates a permanent stoma. Of 266 patients with rectal cancer operated on by Mr Dixon, 13% of patients have required APER and permanent colostomy.

For those people who do require a colostomy, learning to look after a colostomy takes time and patience and we do not expect you to be able to cope with it straightaway. Like anything new it will get easier with time and practice. Within our specialist team we have two trained nurses who will show you how to look after your colostomy and cope with any problems. You may also find it helpful to talk to someone who has already learned to live with a colostomy. If we know from the outset that you will need to have a colostomy, we can arrange for a volunteer to visit and talk to you about the more practical and personal aspects that only come from experience. Before your operation the stoma nurses will carefully plan the best position to site your stoma. Even if we don't anticipate the need for a stoma, we will talk to you and site its potential position should one be necessary.

For the first few days after your operation the stoma nurses will look after your colostomy, emptying and changing the bag as necessary. At first your stoma will be slightly swollen and it can take several weeks before it settles down to its normal size. As you start to feel stronger we will show you how to clean your stoma and change the bags. Several different types of bag or appliance are available and we will help you choose a suitable one. When the nurse is showing you how to look after your colostomy, it may be helpful for a close relative to join you in case you ever have any difficulties once you get home. Before you leave hospital we will ensure that you have a plentiful supply of colostomy bags. When you are at home you can get all your supplies from your local chemist and the supplies are free but you will need a signed prescription from your GP. Once you are home you will still be able to telephone the stoma nurse if any problems arise. We will also arrange for the district nurse to visit you at home for a few days when you leave hospital to make sure that you are coping at home or to sort out any problems that you have with your colostomy. The stoma nurses also hold a weekly (Wednesday pm) clinic in surgical outpatients at Frenchay.

Arrangements will be made for you to be admitted to either Ward 203 or 207 on the day prior to surgery.

Here the nurses will give you a liquid laxative similar to the one you were given prior to the colonoscopy or barium enema. This purgative can cause you to become dehydrated and it is therefore very important that you drink plenty of fluid in the period prior to the surgery. If you are having problems drinking the fluid, Mr Dixon's House Surgeon will give you some fluid directly into your veins. You will not be allowed anything to eat. If your cancer is causing a blockage to your bowel, it may be necessary to undertake the operation without cleaning the bowel beforehand. During this pre-operative time the ward nurses will get to know you and fit you out with some compression support stockings. These can be effective at reducing the chances of you developing blood clots in your legs. Dr Greenslade or Dr Gregory, the Consultant Anaesthetists who work with Mr Dixon, will visit you at this stage and discuss with you any concerns you may have about a general anaesthetic and post-operative pain relief. In particular, they will discuss with you the merits and disadvantages of using either an epidural or patient controlled intravenous analgesia.

How is the Surgery Done?

The operation is carried out under a general anaesthetic which is administered via an injection into a vein on the back of your hand. Once you are asleep you will be positioned on the operating table and a catheter will be introduced into your bladder to monitor your kidney function and to ensure that you don't become dehydrated in the post-operative period. The anaesthetist will also give you a large dose of two intravenous antibiotics to reduce the risks of you developing any infective complications, for example a wound infection.

When you regain consciousness following the anaesthetic in the recovery bay, you will find that you will be connected to a drip and several monitors. The recovery nurses will monitor your progress and pain

relief and once you are deemed stable you will be returned to the ward.

The removal of the rectum and rejoining of the bowel just above the anus is termed a "low anterior resection". This is a major surgical procedure which takes about 3 hours and requires a large incision which is sited down the middle of your tummy and skirts your tummy button. The incision is large to allow for optimal exposure of the contents of your pelvis and mobilisation of the colon. It is also easily closed. We will use an absorbable suture so you do not need to have any stitches removed. Post-operatively we will try to make you as comfortable as possible. Fluids will be restricted to sips of water over the first 48 hours and then increased. We will gradually re-introduce diet after you have passed wind from your bottom and we are happy that all is well. The majority of our patients will be prescribed oxygen for three days following surgery. The apparatus for administering this is a little uncomfortable but we would ask you to co-operate. You will also be seen on a daily basis by the ward physiotherapist to ensure that you are adequately ventilating your lungs. It is very important that you co-operate as it will reduce the chances of you developing a serious chest infection. You will be encouraged to start moving about as soon as possible; this is an essential part of your recovery and, even if you have to stay in bed, it is important to keep up regular leg movements and deep breathing exercises.

Before you leave hospital, Mr Dixon or his Registrar will come and talk to you about the pathologist's report and your particular case will be discussed at the multi-disciplinary meeting. The report is very important in helping us advise you whether or not you require any additional treatments, for example chemotherapy. If that is the case, you will be given an appointment to see Mr Hopkins the following week. Either Mr Dixon's Registrar or SHO will be present when you see Dr Hopkins. Mr Dixon will see you in his outpatient clinic for a post-operative check-up at six weeks. This is a good time for you to discuss any problems that may have arisen after your operation.

What Problems Can Occur After Low Anterior Resection?

Obviously the most serious complication of major surgery is post-operative death. Elective (planned) surgery under the age of 80 has overall an 8% in-hospital mortality. The mortality rises to 16% in patients the age of 80. The in-hospital mortality is higher if there has been an anastomotic (join) leak. In Mr Dixon's experience of 266 rectal excisions, there have been 5 (1.9%) post-operative deaths.

The most common serious complication of low anterior resection is leakage of the join. Regrettably this is quite common and occurs in around 10% of cases. Scrupulous attention to the preparation of the bowel and meticulous attention to the details of the join will obviate this risk. In Mr Dixon's series of 232 anterior resections, we have had 6 (2.5%) leaks. If Mr Dixon is worried about the possibility of an anastomotic failure, he will temporarily defunction the bowel and create a stoma. We find this necessary in about 15% of operations.

This temporary stoma will be closed once the join has healed in about eight weeks' time. If you have received a five-day course of pre-operative radiotherapy we will automatically create a temporary stoma as radiotherapy slows the healing process. Provided all goes well, the temporary stoma will again be closed in about three months' time.

Other complications include bleeding, delayed recovery of bowel function, which may require us to pass a small tube through your nose, down your gullet into your stomach. This will stop you vomiting. You will need to continue receiving intravenous fluids until your bowel has recovered its normal function.

Infection of the wound is a risk but isn't common. If the wound starts to become red then antibiotics may be needed. If pus starts to come out then the wound may need to be opened up to release the infection.

Deep infection increases the chance of a hernia developing where your abdominal wound has been closed.

If you are a smoker, have bronchitis or asthma, you are at risk of developing a chest infection. These are treated by antibiotics, oxygen and physiotherapy. Deep vein thrombosis (clots in your legs) is not an uncommon problem following a long pelvic operation and special precautions will be taken to reduce your risk. Moving your legs and feet as soon as you can after the operation and walking about early all help to stop thrombosis occurring. If you develop a deep vein thrombosis (less than 1% risk) you will be given an anticoagulant to thin your blood. This will be continued for a three-month period. Occasionally a deep vein thrombosis can lead to development of a pulmonary embolus (less than 1% risk) if the clot moves to the lungs. This is a serious and occasionally fatal event. Treatment comprises of Heparin to thin the blood and anticoagulation. Occasionally, a major operation such as this will bring to light hidden pre-existing problems of your heart which may manifest themselves as the heart beating fast and inefficiently or, occasionally, a heart attack. There are risks to any general anaesthetic but precautions are taken to keep these risks as low as possible.

What About the Recovery? Going home: This depends on how fit you are, who is at home with you, how comfortable you are after the operation and any complications that have arisen. A plan may be made for you to go home a week after the operation but many people stay in hospital for 10 days or so. In general, you can go home as soon as you feel able to do so.

Pain and painkillers: People vary a lot in the amount of pain they feel once the epidural or the patient-controlled analgesia has been stopped. Some get very little discomfort but it is common to experience pain during the first couple of weeks, particularly when getting up from lying or sitting and when returning to a chair or bed. The muscles that have been stitched together are active and pulling at those times. Use the painkillers that you have been given to help you to become active and to sleep with comfort. You are likely to get aching and pulling as you become more active during the first month as the tissues are stretched and become supple again. If you need mild painkillers at home then Paracetamol is a very good choice.

Bathing and showering: You can wash the wound carefully with soap and water, bath or shower after about two or three days and when any dressing has been removed. Avoid the use of talc for about a week.

Walking: You can start to walk about as soon and as much as you want, although you will be quite stiff at first and will probably not feel like walking long distances.

Driving: You can start to drive the car when you feel confident to control it in an emergency. Often one month after the operation.

Sex: Once you have recovered from the operation there is no medical reason why you should not take up a normal sex life again. However, you may find that you feel subconscious about the changes in your body's appearance, particularly if you have got a stoma. If you have a supportive partner you may find that talking about your feelings will help you dispel any anxieties. Do not feel guilty or embarrassed to talk to one of the doctors or stoma sisters about what is troubling you. He or she may refer you for specialist counselling if you think that that would be helpful.

Work, sport and heavy lifting: You can return to work as soon as you feel comfortable and confident enough to manage your job. People who work from home or who can go back part-time often do so, say within about six weeks after surgery. If you need to drive yourself or spend all day on your feet then you are unlikely to get back for at least two months. If your job involves heavy manual work or lifting, you should probably not return for about three months.

You can get back to sport and other physical activity as soon as your discomfort allows. It is sensible to start these activities gradually and work your way back to full fitness.

Adjuvant Therapy is given when all the tumour has been removed but the appearances of the tumour under the microscope suggests that there is a good chance that the cancer might recur. This is more likely if the lymph nodes have been affected. The reasons why cancer may spread to other parts of the body are not known, the original cancer may have been released into the blood stream or the lymphatic system and these can sometimes set up tiny cancers or metastases in other parts of the body. These may be so minute that they remain undetected for several years.

Adjuvant Chemotherapy

For a number of years a drug called 5 Fluorouracil has been prescribed as adjuvant therapy for cancer of the colon and the rectum. The activity of 5 Fluorouracil is increased by giving it together with a vitamin called Folinic Acid. To date there has been some 12,000 patients who have received adjuvant chemotherapy as part of 33 randomised trials. The data suggests that chemotherapy reduces the odds of death from colorectal cancer by some 12%. This suggests that for every 100 patients, whose cancer has spread to the lymph nodes, treated for six months with chemotherapy, six deaths will be avoided. We do not know for sure how effective chemotherapy is in patients where the cancer has not spread to the lymph nodes. This is being answered in a prospective clinical trial. Mr Dixon and Dr Hopkins will explain this to you. Research is also continuing to try and determine the most effective way of giving 5 Fluorouracil and the Folinic Acid. Chemotherapy is usually given as a course of treatment over several days. This is followed by a rest period of a few weeks, which allows your body to recover from any side effects of the treatment. The number of courses you will have will depend on the type of cancer, the side effects you are having and how well the tumour is responding to the drugs.

If you have colonic cancer Mr Dixon will discuss with you the pros and cons of placing a small tube into a vein that drains into the liver, at the time of surgery. Chemotherapy is infused continuously into the liver for the first seven postoperative days. When chemotherapy is given in this way, you will experience very few side effects, if any. Using this proven technique, Mr Dixon would hope to gain you an additional 5% survival advantage. Chemotherapy given this way does not work on rectal cancer

Side-effects

Whilst the drugs are acting on the cancer cells in your body, they will temporarily reduce the number of normal cells in your blood. When the white blood cells are reduced you are more likely to get an infection. When the red blood cells are reduced you will become anaemic and may tire easily. During chemotherapy your blood will be tested regularly and, if necessary, you will be given a blood transfusion or antibiotics if you are at risk of an infection. If you develop a high temperature on the treatment you will need to be admitted to hospital to receive antibiotics directly into the blood stream.

Other side effects may include nausea and diarrhoea. Although hair loss can occur, it isn't common. The drugs can also make your mouth sore and cause small mouth ulcers. Regular mouthwashes are important. The oncology nurses will show you how to do these properly. If you don't feel like eating you can replace your meals with nutritious drinks. Dr Hopkins and her team will also prescribe anti-emetics to reduce the feeling of sickness. Although these side effects are hard to bear at times they do disappear once your treatment is over and if you lose your hair it will grow back surprisingly quickly. Not all drugs cause the same side effects and many people have none at all! Dr Hopkins will tell you what problems, if any, to expect from your treatment. Chemotherapy affects people in many different ways and many are able to lead a normal life during their treatment. Just do as much as you like and try not to overdo it.

Adjuvant Radiotherapy

Radiotherapy treats cancer using high-energy rays that destroy the abnormal cancer cells when they are dividing, while doing as little harm as possible to normal cells. Extensive trials have shown that a five-day course of pre-operative radiotherapy is associated with something approaching a 14% survival advantage in patients with rectal cancers. Unfortunately, pre-operative radiotherapy suffers from the major disadvantage of being unselective and its beneficial effects have to be counterbalanced by its side-effects, hence the need for pre-operative staging. In the first four post-operative months, pre-operative radiotherapy is associated with an increased risk of blood clots (deep venous thrombosis and pulmonary

embolus) and heart complications. There is also a greater risk of wound and infective complications. In the long term, pre-operative radiotherapy is associated with an increased risk of hip and pelvic fractures, small bowel damage leading to potential obstruction and bowel fistulas.

Post-operative radiotherapy can also be effective and has been shown to both delay and reduce the risks of developing local (pelvic) recurrence. Unfortunately, the trials have shown no clear evidence of an improved survival. Occasionally, this form of adjuvant therapy would be recommended by Mr Dixon and Dr Hopkins. Pre-operative radiotherapy is given over five days immediately prior to surgery. Post-operative radiotherapy is given over four weeks.

To ensure that you receive maximum benefit from your radiotherapy, it is carefully planned following a series of x-rays of the area we wish to treat. Washable marks will be made on your skin to show the radiographer the exact place to direct the rays. During the course of treatment the area should be kept as dry as possible to prevent the skin becoming red and sore. Before your radiotherapy is given, you will be positioned carefully on the couch and made sure that you are comfortable. During treatment, which only takes a few minutes, you will be left alone. You will be able to talk to the radiographer who will be watching from an adjoining room. Radiotherapy is not painful but you do have to lie still.

What are the Side-effects of Radiotherapy?

Radiation of the bowel sometimes causes nausea, vomiting, diarrhoea and tiredness. Some people also find that they pass urine more often than usual. Most of these side effects can be easily treated with drugs. It is important to let the radiographer or Dr Hopkins know if you are having any such problems. Any side effects will gradually disappear once your treatment is over. Whilst you are having this treatment it is important to drink plenty of fluids, take a healthy diet and get as much rest as possible. Radiotherapy does not make you radioactive and it is perfectly safe for you to mix with other people

throughout treatment.

Follow up

After your treatment has been completed, Mr Dixon will want you to have regular check-ups and these will often continue for several years, although will become less and less frequent. If you have not had a full examination of your bowel by colonoscopy or barium enema we will check the remaining bowel after six months. In some cases we arrange for a liver ultrasound scan at twelve months. Unfortunately, even with follow up as frequent as every three months, most recurrences are discovered as a result of symptoms reported by patients. If you notice any new symptoms in between clinic visits, please let your doctor know. Remember our Specialist Colorectal Cancer Nurse and stoma nurses are available to offer guidance and support.

Members of the multi-disciplinary colorectal cancer team whom you might meet

Surgery

Mr A Dixon - Consultant Colorectal Surgeon

Email: Anthony.Dixon@north-bristol.swest.nhs.uk

Secretary: Maggie Martin Tel: 0117 9186503

Colorectal Cancer Nurse Specialist

Lisa Mackey

Contact No: 0117 9186707

Lesley Aitkin

Mobile No: 0779 9891325

Nurse Specialist – Stoma Care

Sr Angela Reeves

Contact No: 0117 9701212

Sr Claire Price

Ext.3632 or Bleep 1174

Clinical Oncology & Radiotherapy

Dr Kirsten Hopkins

Secretary: 0117 9186597

Dr S Falk

Anaesthetists

Dr G Greenslade

Dr M Gregory

Macmillan Consultant in Palliative Medicine

Dr R Tunstall

Secretary: 0117 9186587

Histopathology

Dr H Rigby

Radiology

Dr A Longstaff

Dr N Slack

Mr R Law (Clinical Radiographer)

Wendy Rayner (Clinical Radiographer)

Colonoscopy

Sister L Wall

Sister C Braybrooke

Chronic Pain Management

Dr S Coniam

Dr G Greenslade

Information Systems

Fiona Braddon

Fran Haynes

Social Worker

Mr J Larcombe (Ward 203)

Surgical Wards

Sister P Foster (Ward 203)

Tel: 0117 9701212 Ext 3203

Sister T Scott (Ward 207)

Tel: 0117 9701212 Ext 3207

Useful Organisations

BACUP

3 Bath Place

Rivington Street

London

EC2A 3JR

0171 696 9003

Freephone: 0800 800 1234

Website: www.cancerbacup.org.uk

British Colostomy Association

15 Station Road

Reading

Berkshire

RG1 1LG

Tel: 01734 391537

Cancer Information Services

Freephone 0800 18 11 99

Cancerlink

17 Britannia Street
London
WC1X 9JN
0171 333 2451

Beating Bowel Cancer
PO Box 360
Twickenham
TW1 1UN

Low cost credit card hotline: 0345 330345

Bristol Ostomy Self Support Group
Secretary: Maurice Cox

Tel: 0117 9401931

The Language of Bowel Cancer

The following terms may be used in relation to bowel cancer or its treatment.

anaemia - reduced number of red blood cells and levels of haemoglobin in the blood.

anus - back passage from which faeces emerge.

biopsy - a small piece of tissue taken from the body to be examined under a microscope.

chemotherapy - treatment of cancer by drugs to kill any cells dividing.

colectomy - removal of the colon by surgery: the large bowel's function is to absorb water and salts. It is about 1½ metres long.

colonoscopy - passing a long, narrow telescope through the anus to view the lining of the colon.

colostomy - the end of the bowel that is brought to the skin surface on the abdomen to form an external channel for the passage of stools.

digital examination - examination of the back passage using a gloved finger.

gastroenterologist - a physician specially trained in the diagnosis and treatment of disorders of the intestines.

gut - a word commonly used for the digestive tract.

inflammatory bowel disease - a general term for chronic inflammatory disorders affecting the small and/or large intestine. Specific conditions include Crohn's disease and ulcerative colitis.

mucosa - the name given to the lining of the bowel which produces a lubricant called mucus.

mucus - a clear, jelly-like substance which lubricates the lining of the bowel to ease the passage of stools.

occult blood - non-invasive blood in the stools which can be detected by a simple laboratory test.

oncologist - a healthcare professional who specialises in chemotherapy and radiotherapy treatments.

polyp - a growth that projects on a stalk from the mucosal lining in the intestine.

prognosis - prediction of what might happen in the future, ie survival.

radiologist - a healthcare professional who specialises in x-ray, ultrasound and CT examinations.

radiotherapy - treatment of cancer by deep x-rays.

rectum - the lowest part of the bowel nearest the anus.

sigmoidoscopy - passage of a short, lighted telescope through the back passage to view the rectum.

stoma - the opening made through the abdomen for the passage of stools.

stoma nurse - a specialist nurse who is highly trained in the care of patients who have a stoma, their carers and families.

Bowel Cancer in the Family

We regard a family history for bowel cancer is significant if it includes:

1. a close relative diagnosed before the age of 45 years or
2. two or more close relatives (parent, child, brother, sister) with bowel cancer, especially when diagnosed under the age of 45.

The general population has a 1 in 35 lifetime risk of developing bowel cancer. The above two groups have an approximately four-fold increased risk of bowel cancer over the general population. Relatives of cases diagnosed between the ages of 45 and 60 have a modest increase in risk of bowel cancer, while the risk of relatives of cases diagnosed after the age of 60 is essentially the same as the population risk.

If you feel there is a significant history of bowel cancer in your family, it would be very useful for you to draw out your family tree to three generations, if possible, noting down illnesses and causes of death in the family. Include cases of bowel cancer and other bowel disorders as well as other cancers, for example stomach, kidney, bladder, breast, ovaries or uterus. Try to give an idea of the age of each family member when their symptoms first appeared and when they died. Do not worry if you do not have all the details but try to be complete as possible.

If Mr Dixon's team feel that you are at an increased risk of bowel cancer, we will arrange to admit you as a day case for a colonoscopy. This involves visual inspection of the lining of the bowel using a thin, bendy tube that is introduced through the anus. Before you have the test you will need to take a liquid laxative to clean the bowel. You will also be given a mild sedative and an intravenous painkiller as some people find the test uncomfortable. If we find any abnormality of the lining of the colon this will be dealt with at the time.

What we do next depends on your age, exact family history and your individual risk of developing bowel cancer and the findings of the test.

We may repeat the test at 5 years or, if you are young and there is a very strong family history, Mr Dixon may refer you to a clinical geneticist. If you are at increased risk, it is important to know that bowel cancer sometimes presents itself through symptoms. If you notice any persistent changes in your bowel habit for several weeks or more you should not ignore the symptoms and go and see your doctor. Whilst there are many conditions apart from bowel cancer which can cause the symptoms, if you are over 50 bowel cancer needs to be excluded. The following symptoms should not be ignored:

- persistent change in bowel habit, either diarrhoea or constipation.

- blood in the stools.

- mucus in the stools.

- stools that are smaller and narrower than usual.

- abdominal pain/cramps.

frequent, sometimes painful wind.
feelings that the bowel does not empty properly.
unexplained anaemia.
unexplained weight loss.

Colorectal Cancer Research Fund

More work is needed to find ways of increasing patient awareness of the symptoms of bowel cancer, improve the effectiveness of its diagnosis and provides patients with the up to date information that they require. We also need to find out how a diagnosis of bowel cancer effects in individuals quality of life in the short and long term. By targeting GP practices, we have increased the proportion of early cancers diagnosed to 60%; 17% were at the earliest stage. This is almost twice the national average.

We need your help today

Mr Tony Dixon and his team at the North Bristol NHS Trust (Frenchay) rely on the generosity of supporters like you to help fund the purchase of special items of equipment not provided by the NHS. We have already been able to purchase an ultrasound scanner to examine the liver for signs of cancer spread during surgery. We would like to purchase additional probes to help direct the optimal choice of surgery and radiotherapy. We have also obtained computers to allow accurate collection and analysis of clinical data – some of which is included in this booklet. Ultimately we would like to fund a dedicated unit. Making a contribution, however small, will help to ensure the continuation of the advances which promise so much.

Please send your donation C/O Cathy Cashman, Finance Dept., Trust HQ, North Bristol NHS Trust, Frenchay Hospital, Frenchay Park Road, Bristol BS16 1LE.

If you have any comments or suggestions, or would like to form a focus group, or meet other patients with bowel cancer, please get in touch with Sr Lesley Atkins or Mr Dixon.