Information for patients receiving Chemo Radiation for Anal Cancer

The Beatson
West of Scotland Cancer Centre
1053 Great Western Road,
Glasgow G12 0YN
This leaflet is for patients receiving radiotherapy and chemotherapy treatment for anal cancer at the Beatson West of Scotland Cancer Centre. It describes the radiotherapy planning and treatment. It also explains the effects you may experience during and after treatment, and how best to cope with them. We treat each patient as an individual and the effects of treatment may vary from one patient to another. Therefore the information enclosed is a general guide and does not mean you will experience all of the effects described. Your doctor, radiographer and clinical nurse specialist will explain this further if necessary.

Before agreeing to this treatment it is also important that you understand its nature and possible effects. If you are in doubt about anything or have any questions or problems, please let us know as soon as possible.
Preparation for Treatment
Before your course of radiotherapy can begin, the treatment must be carefully planned.

Before your planning appointment you may be asked to take a drink called gastrographin. If so, you will be asked to wait an hour between drinking this and having your scan. This helps us to see the structures within the area that will be treated more clearly. You will be given precise details describing your scan with your appointment letter.

You will be asked to undress from the waist down. It may be possible to keep on underwear. Your treatment is planned by radiographers who will advise you about this and will ensure your dignity is maintained by covering you whenever possible.

CT appointment
Your first appointment will be at the CT scanner. This involves a scan taken with you lying on a special couch in the position necessary for treatment. Usually this will be lying on your tummy. At the time of your scan, marks will be put on your skin with a felt tip pen. It is important that you stay as still as you can during the scan. It will only take a few minutes. The x-ray pictures from this CT scan will help your Doctor and Radiographer plan your radiotherapy. Once your doctor is satisfied with your planned treatment, your radiographers will replace the pen marks with a little permanent mark (tattoo) which looks like a tiny freckle. This planning appointment will take about 30 minutes.
**Additional Information**

Sometimes your Doctor may wish to place a piece of wax in the treatment area i.e. between your buttocks. This will be decided at your CT appointment. Each patient is different, so if you are to have this done your Radiographers will guide you through the procedure. You will have to lie on your tummy in the treatment position and the wax will be place in-between your buttocks and moulded to your shape. It will then have to be left in place to dry/harden, at first it may feel soft and warm. This can take approximately 15 minutes. The wax will then be used at each treatment appointment.

**Radiotherapy Treatment**

The treatment will be given on a machine called a linear accelerator which is a special x-ray machine used to give radiotherapy treatment. Your radiographers will explain everything before treatment starts and check you know what to expect and how many treatments you will have. As a guide this can often be between 5 and 6 weeks. Your radiotherapy will be given in small daily doses, Monday to Friday but not at the weekend. It is important that you attend every day for treatment. Please let the Radiographers know if you have any problems.

Each day you come for treatment your radiographers will position you just as you were in the CT scanner or Simulator. The radiographers leave the room while the machine is on but they are monitoring you closely on closed circuit TV while your treatment is being delivered. There is nothing to feel during treatment or immediately afterwards. Your treatment usually takes around 10 minutes. It is important that you stay as still as you can during treatment and breathe normally. Please speak to your radiographers if you have any questions or problems.
Chemotherapy and Radiotherapy

It is common for chemotherapy to be delivered alongside radiotherapy for anal cancer. The chemotherapy makes the cancer cells more sensitive to the radiotherapy. There are different kinds of chemotherapy drugs used to treat anal cancer. Sometimes they may be being given as part of a clinical study (trial). Your doctor will talk to you about the drugs and trials and will answer any questions you might have.

We will give you more specific information about your chemotherapy once you and your doctor have decided on which treatment you will have.

General Advice During Treatment

There is no reason to change your lifestyle during treatment, but it may help to:

- Try to get plenty of rest and sleep, especially when the treatment begins to make you tired, but it is important that you try to continue some of your normal daily activities and interests. A sensible balance between rest and activity may be best.

- Accept offers of help from family and friends if you need help around the house. This also allows them to feel involved in caring for you during this time.

- The specialist colo-rectal nurse or radiographer will see you every Thursday at the review clinic while you are having treatment as an out-patient. They will help you with any problems you may experience during treatment.
Early Effects of Radiotherapy Treatment

Skin: Your skin within the treated area will become pink or red and increasingly sensitive. This will ultimately become painful and symptoms tend to develop a few weeks into treatment. It is likely your skin around the back passage, around the genitals, the groins and the tops of the legs will be affected and if so this will need to be closely monitored by the specialist nursing staff. We can prescribe creams that will help soothe the skin reaction but do not be tempted to use anything other than those prescribed here at the Beatson. However soothing they may seem, they may interact with your treatment and cause your skin to become worse.

Caring for Your Skin

- You may bath or shower, but don’t have the water too hot (lukewarm). You may use mild unperfumed soap. Pat your skin dry with a soft towel.

- Do not use perfumed soaps, creams or lotions on the treated area, as these may irritate your skin.

- You will find that you may be more comfortable if you wear loose fitting clothes and underwear, preferably with cotton next to your skin during treatment and for 3-4 weeks after radiotherapy.

Please remember that after your treatment has finished your skin will not heal immediately and it may even become worse over the following 2 weeks. To ensure your skin is cared for appropriately we will arrange a visit from your district nurse after treatment ends. Your specialist colo-rectal nurse or radiographer at the Beatson will ensure that you have suitable supportive care available before you finish treatment.
**Pain:** Please tell staff if you experience pain as painkillers and dressings can be provided to give relief.

**Opening your bowels frequently:** You may develop the urge to go to the toilet more frequently. You may have this sensation at the start of your treatment as a consequence of the tumour, however as the treatment progresses the back passage becomes inflamed by the treatment and opening your bowels can become painful. It is also likely that you will develop diarrhoea during treatment. This may be accompanied by colicky or wind pains. Your doctor/nurse specialist can prescribe medication to help this. You should also drink plenty of fluids to replace water lost because of diarrhoea. You may notice a discharge of mucus from the back passage and a little blood during this time.

If you have piles (haemorrhoids) or have had these treated in the past, they may get worse during treatment. Let us know, and your doctor/nurse specialist can prescribe something to help.

**Passing water:** Your bladder can also become irritated and you may feel that you need to pass water more often and more urgently than usual. You may also experience a burning sensation, a bit like cystitis, when passing urine. It may be necessary to insert a catheter to relieve this. Drinking plenty of water will help, but let us know so that we can check there is no infection present.

**Nausea:** Please let us know if it is troublesome and we can prescribe medication to help.

**Diet:** When you are having radiotherapy it is important to eat well and choose from a wide variety of foods to help you feel stronger and more able to cope with treatment. Keep to a
normal diet at the start of treatment, although it is best to avoid foods that you know make your bowels move unduly, for example prunes, rhubarb, hot spicy foods etc. It’s also best to cut down on large amounts of fruit juice, fruit and vegetables if you start to have diarrhoea.

**Women:** The tissues of the vagina will be irritated by the treatment. The vagina becomes inflamed during treatment which may make it sore. You may find that sexual intercourse is uncomfortable. You may be a little drier than before and find it a little uncomfortable at first and you may find it helpful to use a lubricant. There are several brands available such as KY Jelly or Replens. It is a matter of finding one that suits you best. Please discuss this with your doctor/nurse specialist if you want further advice. There are also other female professionals available who would be happy to discuss any concerns. Ask your doctor, nurse or radiographer to put you in touch.

**Contraception:** infertility is a late effect of treatment therefore you will need to take contraceptive precautions from the start of treatment to avoid pregnancy.

**Men:** The tissues around and underneath the scrotum may be particularly affected by the radiotherapy. This can be minimised by trying to lift the scrotum up before lying on the couch before treatment. Your radiographers and doctor will give you further advice about this.

**Hair:** The chemotherapy used in anal cancer treatment does not generally cause visible loss of hair from the head but it is likely there will be loss of body hair within the radiotherapy treatment area. This is usually temporary, although in some patients it may not fully re-grow.
Late Effects of Treatment

We believe the benefits of your treatment outweigh any longer-term risks involved, however you need to be aware that in addition to the side-effects which occur whilst you are receiving treatment other potential longer-term side-effects can occasionally occur. It is important to emphasise the likelihood of these effects is small and varies from one person to the next. Your doctor will explain specific individual issues to you; therefore the following is a general guide.

- If you have an operation after your radiotherapy, the treatment may slow down the healing of any surgical wound in the treatment area.

- It is possible your bowel habit may not return to normal after treatment. Your bowels may get looser or become more frequent than prior to treatment. Occasionally medication may be needed to regulate your bowel on a longer-term basis.

- You may develop the urge to go more frequently to the toilet. About a year after the treatment is complete small blood vessels can occasionally form within the bladder or the rectum. These vessels are more delicate than normal and may occasionally break down producing blood in the urine or the bowel motion. You should let your GP or specialist know as they may wish to arrange further tests.

Serious problems are very rare. Scar tissue may develop in several areas. Occasionally it can affect the wall of the bladder and very rarely this can cause shrinkage of the bladder. This can cause irritation on passing water and occasionally making it difficult for patients to “hold on”, requiring them to get to a toilet urgently.
• If such scar tissue affects the bowel it can add to the problems of diarrhoea. Very occasionally this may lead to narrowing or even a blockage in the bowel and an operation may be required to remove this narrowed area. Fortunately this is a very rare problem, but please speak to your doctor if you are worried.

• A very rare but potential effect is that radiation can cause tumours. Although this is a serious possible consequence of your radiotherapy, it is important to bear in mind that it is extremely rare. If it does happen it is likely to be many years after treatment has ended.

Relationships and Sexual Function

It is important to remember that your emotions and worries can play a part in difficulties in your intimate relationships, particularly at this time. There are staff available in the department who can help you talk through any issues, so please let us know if you would like to see someone.

Following your treatment there is a possibility of loss of sexual function.

Men may find it difficult to get or keep an erection due to damage to some of the pelvic nerves. It is important to be aware of this and help and advice is available so please let your doctor know if this becomes an issue. It is highly likely you will become infertile as a result of the radiotherapy and if this is a concern we can arrange discussions with specialists to store sperm before treatment starts.

Women who are still having periods before radiotherapy are very likely to go through the menopause due to the effect the radiotherapy has on the ovaries. This means you will become infertile and develop menopausal symptoms. As discussed
earlier, women receiving treatment may initially notice some vaginal dryness. If this continues to be a long-term problem you should discuss this with your doctor, as help and advice is available. Possible scarring in the tissues of the vagina may contribute to some discomfort during intercourse. We will give you advice about vaginal dilators which can be used to help keep the vagina supple. Please ask if you have any questions or concerns.

With all of these effects above, we must stress that these are potential effects. This does not mean that you will experience all of them. Please remember any of these small risks should be considered against not treating the tumour with radiotherapy.

**After Treatment Ends**

Any symptoms that have developed during treatment will wear off a few weeks after it ends. However the tiredness will probably take a bit longer. You may begin washing normally once your skin no longer looks red or feels itchy. Your district nurse will see you regularly after treatment and will be able to advise you as to when you may return to your normal washing routine. Your oncologist will arrange to see you 4-6 weeks after the treatment has ended either at the Beatson West of Scotland Cancer Centre or the hospital you first met him / her. In certain instances your doctor may want to give you some further treatment but this will be discussed fully with you if it is required.
Where can I Get Help?
Information and Support

All our staff are here to make sure your treatment goes as smoothly as possible and will try to help with any questions or problems you may have. Further specialist help and information is available from:

- Colorectal Nurse Specialist
  Tel: 0141 301 7691/7693

- Information and Support Radiographer
  Tel: 0141 301 7427

- Macmillan Information Radiographer Counsellor
  Tel: 0141 301 7423

We have an Information Centre on Level 1 where you can find further information and signposting to other services.

Tel: **0141 301 7390**

The Cancer Centre has a Radiotherapy Advice Line available for patients who have completed treatment and have a non-urgent query. This is an answer phone service, available from Monday – Friday. Please leave your name and contact number and we will call you back as soon as possible.

Tel: **0141 301 7432**

The Cancer Centre also has a Cancer Treatment Helpline for Urgent Calls. This is for patients on or within 6 weeks of treatment who have urgent or severe symptoms. The line is available 24 hours for emergencies, although it would be helpful if you called early in the day if this is at all possible.

For Urgent Calls Tel: **0141-301-7990**
Counselling and Clinical Psychology

This leaflet deals with the physical aspects of your treatment, but your emotional well being is just as important to us. Being diagnosed with cancer can be a deeply distressing time for you and those closest to you. Within the department we have a counselling and clinical psychology service that can help with worries and difficulties you might be having. If you think this may be helpful to you, please ask staff to put you in touch.

There are also voluntary organisations providing information and support. These include:

- **Macmillan Cancer Support.** 0808 808 0000 www.macmillan.org.uk
  Provides practical, medical, emotional and financial advice for those affected by cancer.

- **Maggie’s Gartnavel:** 0141 357 2269

- **Maggie’s Centre, Wishaw General Hospital** 01698 358392
  Maggie’s Centre provides a comprehensive cancer support programme for people and their families affected by cancer.

- **Cancer Support Scotland (Tak Tent)**
  The Calman Cancer Support Centre, Gartnavel Complex.
  Freephone 0800 652 4531 or 0141 337 8199
  Provides emotional and practical support on a one-to-one basis and through community based groups. Complementary therapies available.
• **Macmillan Benefits Team** (within the Beatson)  
  0141 301 7374  
  Provides free and confidential advice for people affected by cancer and their carers.

• **Beatson Cancer Centre** – if you want to find out more about our Centre please visit www.beatson.scot.nhs.uk

• **The Colostomy Association**  
  provides practical help, support and reassurance to people living with a colostomy.  
  24hr helpline 0800 328 4257  
  www.colostomyassociation.org.uk

• **NHS 24**  08454 24 24 24