Patient information on external beam radiotherapy for bladder cancer

Side effects of bladder radiotherapy

This leaflet will help you understand:

- the radiotherapy side effects you might experience.
- how best to care for yourself during and after treatment.

Our radiotherapy teams have written this information to give you a clear overall picture. Remember, we make your treatment just for you. Your team will inform you of any differences that apply to your care.

What are the side effects and how do I manage them?

Most side effects from radiotherapy only happen in the area being treated. Side effects affect people in different ways.
There are two types of side effects:

- Early and short-term. These can start during your course of radiotherapy. They usually get better by two to six months after finishing radiotherapy.
- Late and long-term. These are side effects that may happen many months or years after radiotherapy. Some of these side effects may not go away. Sometimes we may give you medicine to help.

How likely am I to get a side effect?

Words are used to explain how likely you are to get side effects

Word	How many people will get these side effects?
Expected	50 to 100 people out of 100 people
Common	10 to 50 people out of 100 people
Less Common	less than 10 people out of 100 people
Rare	less than 1 person out of 100 people

Your radiotherapy team will talk about these with you. They will tell you if anything is different for you. You may not get all the side effects discussed in this leaflet. Please ask your team if you have any questions.
Please remember your radiotherapy team have seen these side effects many times before. There is no need to feel embarrassed. To make sure they can look after you in the very best way, please let them know about any side effects you have.

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How do I care for my skin during and after radiotherapy?

- Wash your skin gently with soap and warm water. Pat it dry — do not rub.
- Apply Sodium Laurel Sulphate free creams (e.g., AquaMax®, Epimax®, E45®, Aveeno®, Aloe Vera Gel, CeraVe®) in the morning and evening.
- Do not use thick creams or creams with a lot of paraffin or petroleum jelly.
- If your skin becomes sore, please speak to a member of your radiotherapy team.
- Do not use zinc oxide creams such as Sudocrem®.
- Avoid wet shaving in the treated area.
- Do not use wax or hair removal creams on the treated area.
- Wear clothing that protects the treatment area from the sun. Wear loose fitting clothes made of natural material such as cotton.
- Do not use sun lamps or sun beds.
- Do not apply cold or heat packs like a hot water bottle.
- You can swim in a chlorinated pool but stop if the skin becomes sore. Take a shower in chlorine-free water after your swim and apply moisturiser.
- Avoid hydrotherapy pools, jacuzzis, saunas and steam rooms.
- Radiotherapy causes changes to the skin that makes it more sensitive to the sun forever. Your skin will burn more easily and take longer to heal. During and after treatment, keep the treated area out of strong sunlight. Once your skin has healed, cover the area with clothing when it is sunny. If you cannot cover it, use a high-factor sun cream — at least factor 50, with a minimum UVA 5-star rating. This is important in summer and in hot countries. Your GP might be able to prescribe sun cream if you have had radiotherapy.

Follow the skin care advice from your radiotherapy team. You can also find guidance from the Society of Radiographers **here** or by going to: **https://www.sor.org/news/radiotherapy/scor-updates-radiation-dermatitis-guidelines**

What are the early and short-term side effects?

Expected (50 to 100 out of 100 people)

- **Feeling very tired** – this can feel different for everyone. Try to keep to your normal lifestyle but listen to what your body is telling you. If you feel tired, please rest. It may be helpful to do some gentle exercise, such as walking.
- **Needing to wee more often than is normal for you** and a sudden urge to pass wee. You might also have pain when you urinate (called cystitis).
    - Tips: Try to drink at least 2 litres, which is 4 pints of fluid every day. Avoid drinking caffeinated tea and coffee. You could change to decaffeinated

tea and decaffeinated coffee (decaf). You should drink very little or no alcohol.

- **Runny poo with slime coming out of the back passage** tell your treatment team. You may be asked to change what you eat and given medicine. Everyone is different, the advice given to you will depend on the area being treated and any other treatment you are having or have had.

- **More wind coming out the back passage than usual**
  Tips to help reduce wind during radiotherapy:
  - Try to eat at the times you would normally eat. Do not cut out meals.
  - If you know a food or drink causes you to have wind, do not have it during your radiotherapy
  - Avoid fizzy drinks and beer.
  - Avoid very fatty food.
  - Avoid beans and pulses (some common pulses include: chickpeas, lentils, kidney beans and peas.)
  - Avoid vegetables such as: broccoli, cabbage, cauliflower, Brussels sprouts, onions, garlic and leeks.
  - Do not chew gum.
  - Chew food slowly.
  - Drink peppermint tea.
  - Keep active and try to exercise.

If you need help with your diet, please ask your Radiographer about seeing the dietician.

Common (10 to 50 out of 100 people)

- **Slower flow of your wee compared to normal**
- **Needing to poo more often** – needing to go to the toilet to poo more often than normal, and a sudden urge to poo

If you have a vagina:

- **Vaginal discomfort or more discharge than usual**

Less common (less than 10 people out of 100 people)

- **Hair loss in the treatment area** ask the team treating you where this is
- **Skin soreness, itching, and colour changes in treatment area**
  Your skin may change colour in the treated area. If you have white or light skin, it may turn pink, red, or darker. If you have brown skin, it may turn maroon or darker. If you have black skin, it may get darker, and you may also notice yellow, purple, or grey areas.

What can I do to make the skin reaction less?

- Keep your skin clean during treatment.
- Wear cotton knickers or pants. Avoid tight clothing. This will help to keep the skin cooler and reduce rubbing to the treatment area.
- Do not smoke.
- Drink plenty of water.
- Eat a healthy, balanced diet when you can.

- **Pain and discomfort in your back passage** – due to swelling. This may get worse when you need to poo. This may also affect your sex life if you receive anal sex.
- **A feeling of not completely emptying your bowels after doing a poo**
- **A little bit of blood in your wee or in your poo**

Rare (less than 1 person out of 100 people)

- **Not being able to pass wee**, you might need a tube put into your bladder to help
- **Wee leaking when coughing and straining**

There may be other rare risks that your care team will discuss with you, if anything is different from the side effects listed.

What are the late and long-term side effects?

These are side effects that may happen many months or years after radiotherapy. Some of these side effects may not go away. Sometimes we may give you medicine to help.

Expected (50 to 100 out of 100 people)
If you have ovaries and a womb:

- **Periods will stop if you have them and you will go into menopause** – symptoms of this may start during or shortly after radiotherapy. Egg and hormone production will stop. You can find out more about this by going to the Menopause and Cancer website. The details are at the end of this information under ‘national support services’.
- **Infertility** – you will be unable to carry a pregnancy in the womb after bladder radiotherapy. You may find sexual intercourse uncomfortable during radiotherapy, if so, you should not have sexual intercourse until the soreness has stopped. If you do have sex, you **must** use birth control during radiotherapy.

Common (10 to 50 out of 100 people)

- **Needing to wee** more often than normal and/or a sudden urge to wee
- **The bladder isn't able to hold as much wee as before**
- **Loss of orgasm**

If you have a penis:

- **Changes in ejaculate (the fluid that comes out of your penis when you have an orgasm) –** such as a reduced amount, dry, change in how it feels, or blood-stained
- **Not able to have an erection good enough to have sex**

If you have a vagina:

- **Shrinkage or scarring of the vagina** – this may make vaginal sex difficult. It can also make the comfort and quality of a vaginal exam worse. Your team may advise you to use vaginal dilators after treatment, which may reduce this risk.
- **Loss of orgasm**

Less common (less than 10 people in 100 people)

- **Pain when you wee** – due to bladder swelling
- **Wee leaking when coughing and straining**, you might need to wear pads
- **Not being able to empty your bladder properly**
- **A narrowing in your water pipe** which runs from your bladder to outside your body, you might need to have an operation to help this
- **Blood in your wee or poo**
- **Needing to poo** more often than normal
- **A sudden urge to poo**
- **Watery poo with more slime or wind**
- **Swelling of the back passage** which may cause pain when needing to poo. This may also affect your sex life if you receive anal sex.
- **Pain in your tummy** that comes and goes

Your doctor or the Therapeutic Radiographers will be able to tell you if they are treating your lymph nodes in your pelvis. You would have been told about this before starting treatment. If you had treatment to your lymph nodes you could also have:

- **Swelling in your legs and your private areas (genitals)**

Rare (this means less than 1 person out of 100 people)

- **Pelvis and hip bone thinning** which can cause them to break
- **Bowel / bladder damage which may need an operation –** due to a hole or unusual connection between two parts of your body. You might also have a blockage or a lot of bleeding
- **A bigger risk of a different cancer in the treatment area**

Your doctor or the Therapeutic Radiographers will be able to tell you if they are treating your lymph nodes in your pelvis. You would have been told about this before starting treatment. If you had treatment to your lymph nodes you could also have:

- **Problems with nutrient absorption –** How much goodness your body can get from the food you eat.
- **Damage to nerves** which could cause pain, numbness, or weakness in your legs.

Many of these late side effects are often referred to as pelvic radiation disease (PRD). You can find out more by going to the Pelvic Radiation Disease Association website. The details are at the end of this information under 'national support services'.

We understand some of these side effects sound worrying. The advantage of giving you radiotherapy outweighs any of the risks. Your medical team have looked at all the risks for you and will talk to you about them.

Where can I get more advice and support?

- **Your Radiotherapy Team**: Can answer any questions about your treatment. If you are having any problems related to your radiotherapy after treatment, contact them.
- **How to contact your radiotherapy team**: You will be given their contact numbers at the start of your radiotherapy. If you can't find the numbers, please ask for them and then keep them handy in case you need urgent advice. We will also give you contact numbers when you finish your radiotherapy treatment.
- **National Support Services**:

Cancer support charities, such as Macmillan and Maggie's, offer information, counselling, and support groups.

- Macmillan website: **www.macmillan.org.uk**
- Macmillan Support Line: **0808 808 0000**
- Maggie's: **www.maggies.org**
- Action Bladder Cancer UK: **www.actionbladdercanceruk.org**
- Pelvic Radiation Disease Association: **www.prda.org.uk**
- Menopause and Cancer: **www.menopauseandcancer.org**

What should I remember?

- Your radiotherapy team has seen these side effects many times before, so there is no need to feel embarrassed. To make sure they can look after you in the very best way, please let them know about any side effects you have.

- Your radiotherapy team has planned your treatment just for you.
- This leaflet gives general information. Always follow the advice your team gives you.
- Your team will tell you if anything in this leaflet does not apply to you.
- If anything is not clear, ask your radiotherapy team.
- The key points above should help you prepare and know when to ask for help.

We worked with patients to write this leaflet. We welcome your feedback. To share your thoughts anonymously, scan the QR code or visit:
https://forms.office.com/e/6spj6B4HQk

For more information about radiotherapy, visit:
www.eastofenglandradiotherapynetwork.nhs.uk and click on 'Information for patients'.