Radiotherapy to the pelvis and abdomen

Radiotherapy Department
Paediatric information series

No 4
If you need a large print, audio or translated copy of the document, please contact us on:

020 3447 3711 (Direct line)
020 3456 7890 ext 73711/bleep 1458
0845 155 5000 ext 73711/bleep 1458

We will try our best to meet your needs.
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**Introduction**

This booklet has been written for parents and carers whose child is receiving radiotherapy treatment to the abdomen or pelvis for Wilm’s Tumour, a Neuroblastoma, a Sarcoma, or some other condition. The booklet explains the side effects your child may experience during and after treatment, and how best to cope with them.

We understand that this is a worrying time for children and their families. You may feel that you have been given lots of information about your child’s treatment.

We hope this booklet answers some of your questions. If you still have any questions or concerns, please ask. We are here for you.

**Preparation for young children and young people**

Before your child starts his/her radiotherapy planning and treatment, you and he/she will have a chance to read through the appropriate preparation books. These books explain the whole process from a young person’s point of view.

Whenever possible, and especially with younger children, we plan separate visits to the mould room, CT scanner and treatment machine in advance of the actual treatment. This gives you and your child an understanding of what to expect through treatment.

This ensures your child is comfortable and familiar with what is going to happen. It will also give you a chance to meet the radiographers who will be treating your child, and give you and your child the opportunity to ask any questions.

**For more information about these visits you may contact the radiotherapy department play specialists on 020 3447 3792.**
Side effects during treatment

There will be some side effects which will gradually appear during your child's course of radiotherapy. These effects can vary from patient to patient. There are side effects occurring during treatment, some happening soon after treatment, and some appearing months or years after radiotherapy. The risk and severity of side effects occurring will depend on the dose of radiotherapy given and the exact area which receives the radiotherapy.

We give radiotherapy treatment in addition to surgery and/or chemotherapy. Patients receiving chemotherapy in addition to radiotherapy may experience more severe or additional side effects to those listed here, depending on the drug regimen used. The doctors will discuss these issues with you and your child. The main side effects that occur during treatment are:

**Skin changes**

The skin in the area being treated may become slightly pink and feel warm to the touch. In some cases the skin may appear flaky and itchy during the radiotherapy treatment.

In children who are having pelvic radiotherapy, the perineum (the area of skin between the anus and the genitals) may become red and inflamed. In some cases the genitals (if they are included in the treatment area), may become red and irritated.

During the course of treatment we advise that you or your child wash his/her skin gently using warm water and a non perfumed soap. Your child may bathe normally, but do not use any perfumed bath gels or oils and only use warm water. Please do not allow them to soak in a hot bath as this will irritate his/her skin.

Pat your child’s skin dry with a soft towel. Do not vigorously rub the skin in the treatment area. If the pelvis is being treated, pay particular attention to areas such as the perineum, genitals and any other skin folds.
Do not use any other talcs, creams or lotions in the area being treated unless advised by a member of staff.

Aqueous cream may be applied to the treated skin. This is a simple, unperfumed moisturising cream which you will be given at the start of treatment. This cream can be used from the start of treatment. It helps prevent the skin from becoming too dry. Smooth a little cream very gently onto the treatment area two to three times per day. If the skin becomes too tender and sore do not use aqueous cream. Your child will be referred to the nurses for advice.

Avoid exposing the area to strong sunlight or extreme temperature changes during and after treatment. Ensure your child wears a top to protect his/her skin if they are having their abdomen treated.

Radiotherapy causes changes to the skin which make it more sensitive to the sun. The skin in the treated area will be especially sensitive for the first twelve months after treatment. Therefore, you should avoid exposing the treated area to strong sunlight. After this time, your child can gradually increase his/her sun exposure but we recommend that you always use a high protection sun cream (Factor 25–50 or more) in strong sunlight.

Feeling sick
Following a treatment session some children may feel sick (nauseated) and vomit, particularly if radiotherapy is given to the abdomen. Your child will have been prescribed regular anti-sickness medication to take during treatment, which may cause constipation. However, if they are still experiencing symptoms it is important to inform a member of staff who can refer you to a doctor for further medication. Please ask for a copy of the leaflet “Coping with nausea”.
Diarrhoea
About two weeks into treatment your child may experience loosening of the bowels. This is a normal reaction. This is due to the radiation irritating the bowel. Your child may also experience wind pains and/or cramping sensations. Your child may be prescribed regular anti diarrhoeal medication whilst they are on treatment.

If the diarrhoea persists or becomes severe the doctor will prescribe stronger medication. The radiographers will also offer advice on nutrition or refer your child to the dietitian who can offer advice on maintaining a nourishing and pleasant diet. It is important that your child maintains a good fluid intake if this is a problem (between one to two litres a day). This can include water, squash or hot drinks. Please ask for a copy of our leaflet on “Coping with constipation or diarrhoea”.

Effects on the bladder
If your child is receiving pelvic radiotherapy it is possible that he/she may experience a burning sensation on passing urine, and also an increase in the need to pass urine. This is due to the radiotherapy irritating the bladder and is called “radiation cystitis”. If your child experiences such symptoms please inform a member of staff. Your child will be sent for a urine test to check that it is radiation cystitis and not an infection. It may help if your child increases their fluid intake. Drinks such as cranberry juice have been found to help.

Blood and bone marrow system
Treating the abdomen and pelvis may affect the bone marrow. Bone marrow makes blood cells and is found in the centre of bones such as the spinal bones. The white blood cells (which fight infection) and platelets (which are important for blood clotting) might be affected. Your child’s blood count will be monitored as radiotherapy treatment progresses. Regular blood tests will be required. You will be informed of the number of blood tests required at the start of treatment.
This can either be done at University College London Hospital or via your home care team. If your child requires a blood transfusion, this will be arranged with T11 Paediatrics (for children under 13) or T12 Adolescents (for children over 13).

**Appetite**
It is important that your child tries to eat a well balanced diet during radiotherapy treatment, and to drink plenty of fluids, between one and two litres a day. This can include water, squash or hot drinks. Some children do experience a loss of appetite. This may be due to a number of factors; anxiety about unfamiliar surroundings, side effects of treatment. Your child will be weighed weekly by the radiographers and if there is a significant weight loss your child will be referred to the dietitian. Please ask for the leaflet “Eating hints for patients”.

Your child’s appetite may be suppressed for a number of weeks or months from the end of treatment, but they will be closely monitored by the medical team.

**Tiredness and fatigue**
A course of radiotherapy may make your child more tired. This occurs towards the end of treatment and in the following weeks. This is a normal reaction to the radiotherapy. Allow your child to rest if the need arises. Let them set their own pace. However, many children do not have a problem with tiredness and should be encouraged to lead a normal life as much as possible. Please ask for our leaflet “Coping with fatigue and tiredness”.

If the tiredness is very severe, it is important to exclude any hormone deficiency by a blood test. Your child will be referred to the endocrinologists (doctors specialising in glands) who will monitor this.
Late side effects of radiotherapy
Late side effects incurred during treatment can appear to develop months or years after radiotherapy has finished. They are the hardest to predict and, unfortunately, when they do occur they are permanent. Your child’s radiotherapy doctor will have explained to you the potential late side effects of radiotherapy as part of the consent process. These may include:

Growth
Radiotherapy will affect the growth of bones and soft tissues in the treated area. In younger children this will mean that the treated area will be smaller, thinner or less muscular than the untreated areas. The radiation may affect the growth of the vertebrae (the bones of the spine) and the pelvic bones if they are included in the treatment field. There might be some underdevelopment of these bones, with some loss of height and a small waist. The loss of height is unlikely to be more than two inches and will probably be less, but this will depend on your child’s age at treatment. However, if you are concerned please speak to the radiotherapy doctors. Your child will be monitored in a growth clinic.

Bowel problems
The severity of potential problems on the bowel depends on the dose of radiotherapy given. The symptoms may vary from mild diarrhoea to bleeding. However, sometimes after surgery and radiotherapy the tissue surrounding the bowel can stick together (adhesions), and this can sometimes require further surgery to correct. This is a rare problem, but please do speak to the doctors if you are worried.

Bladder
The bladder may shrink in size and be slightly smaller after radiotherapy. This may mean your child passes urine more often. Rarely, some bleeding may occur in the urine. This is not usually serious, but if it occurs it is important to let your child’s GP, specialist nurse or doctor know. They may wish to arrange further tests.
Female fertility
In girls it is likely that radiotherapy to the abdomen and pelvis will mean treating both ovaries and the uterus (womb). This will almost invariably cause pubertal arrest and infertility, in which case hormone replacement therapy will be necessary. Some young girls may apparently recover ovarian function and retain a small window of fertility as adults. The doctors will discuss this with you and your child.

Male fertility
In boys it is often possible to avoid treating the testes, but sometimes it cannot be avoided. The doctors will be able to tell you if the dose to the testes is likely to cause infertility or affect the production of the male sex hormone testosterone. In either case your son will be referred to an endocrinologist to discuss the possibility of sperm banking (please ask for a leaflet), or to discuss the implications on growth and sexual maturation.

Second malignancy
Very rarely, children who have received treatment for one particular tumour may develop another type of tumour in the treated area some years later. Recently intensified chemotherapy treatment regimens to improve cure rates may further increase this possibility.

The radiotherapy doctors will discuss this with you if it is relevant to your child. Other factors such as smoking and excess sun exposure may also lead to an increased cancer risk in later life. It is therefore very important that any child who has received this treatment never smokes and always takes precautions against excess sun exposure.
Support
This booklet deals with the physical aspects of your child’s treatment, but their emotional wellbeing and that of the family is just as important. Having treatment can be deeply distressing for your child and the family. Within the radiotherapy department there will be access and support from the radiotherapy play specialists, the Macmillan information and support radiographer, the treatment radiographers and the radiotherapy nurses. However, if your child requires further medical or emotional support he/she can be referred to a variety of health professionals specialising in children’s and young people’s needs.

All the staff are here to make sure your child’s treatment goes as smoothly as possible, and to support the family through this difficult period. We will try to help you with any questions or problems you may have.

After your child’s radiotherapy has finished
Once your child has finished radiotherapy treatment you will be given a follow-up appointment to see the radiotherapy doctors in about four weeks time. This will either be at Great Ormond Street Hospital or at University College London Hospital.

The side effects your child may have experienced will continue after radiotherapy treatment has finished. It is common to experience a worsening of the skin reactions for about 10 to 14 days after radiotherapy. Please feel free to contact the department, your child’s specialist nurse, the nursing staff or the Macmillan information and support radiographer if you are worried. You could also contact your child’s GP or call outpatients to request an earlier follow-up appointment. However, most of the side effects should resolve after your child has finished treatment. Before your child completes his/her course of treatment please ask for a copy of the leaflet “Finishing treatment”.
Useful contact numbers

Local

Radiotherapy Play Specialists:
Laura Walter
Direct telephone: 020 3447 3792
Main switchboard: 0845 155 5000
ext 73792/bleep 2268
Alternative switchboard: 020 3456 7890
ext 73792/bleep 2268

Rhonda Alexander, Hannah Pollard
Direct telephone: 020 3447 3792
Main switchboard: 0845 155 5000
ext 73792/bleep 1138
Alternative switchboard: 020 3456 7890
ext 73792/bleep 1138

Macmillan Information and Support Radiographer:
Mark Williams
Direct telephone: 020 3447 3711
Main switchboard: 0845 155 5000
ext 73711/bleep 1458
Alternative switchboard: 020 3456 7890
ext 73711/bleep 1458
Email: mark.williams@uclh.nhs.uk

Radiotherapy Care Team:
Direct: 020 3447 3729
Main switchboard: 0845 155 5000
ext 73729
bleep 1138/2075
Alternative switchboard: 020 3456 7890
ext 73729
bleep 1138/2075
**National:**

**The Neuroblastoma Society**  
Helpline: 020 8940 4353  
Email: secretary@neuroblastoma.org.uk  
Website: www.nsoc.co.uk

**Sarcoma UK**  
Telephone: 0158 487 8497  
Email: info@sarcomauk.org  
Website: www.sarcomauk.org

**The Wilms Tumour Resource Directory**  
Website: www.cancerindex.org/ccw/guide2w.htm

**Ewings Sarcoma Resource Directory**  
Website: www.cancerindex.org/ccw/guide2e.htm

**CLIC Sargent**  
Freephone helpline: 0800 197 0068  
(Monday to Friday 09:00 to 17:00)  
Email: helpline@clicsargent.org.uk  
Website: www.clicsargent.org.uk

**Click 4 (Information website for teenagers on cancer)**  
Website: www.click4tic.org.uk

**Teenage Cancer Trust**  
Telephone: 020 7612 0370  
Email: tct@teencancertrust.org  
Website: www.teenagecancertrust.org

**Teens Unite**  
Telephone: 0199 244 0091  
Email: info@teensunitefightingcancer.org  
Website: teensunitefightingcancer.org
Help Adolescents With Cancer
Telephone: 0161 688 6244
07718 801013 (Anytime)

Email: niki@hawc.fsnet.co.uk
Website: www.hawc-co-uk.com

Gaps:line
Telephone: 0845 121 4277
(Monday to Sunday 08:00 to 22:00)

Email: enquiries@gaps.uk.com
Website: www.gaps.uk.com

Contact A Family
Telephone: 0808 808 3555
(Mondays 10:00 to 16:00 and 17:30 to 19:30
Tuesday to Friday 10:00 to 16:00)

Email: info@cafamily.org.uk
Website: www.cafamily.org.uk

Christian Lewis Trust Cancer Care for Children
(Family care services and helpline)
Telephone: 0179 248 0500

Email: enquiries@christianlewistrust.org
Website: www.christianlewistrust.org

Youth Cancer Trust
Telephone: 0120 276 3591
(Monday to Friday 9:00 to 17:00)

Email: admin@yct.org.uk
Website: www.yct.org.uk
Childrens Cancer and Leukaemia Group (CCLG)
Telephone: 0116 249 4460
Email: info@cclg.org.uk
Website: www.cclg.org.uk

National Alliance of Childhood Cancer Parent Organisations
Telephone: 0178 560 3763
Email: ro@naccpo.org.uk
Website: www.naccpo.org

Macmillan Cancer Support
Cancerline Freephone: 0808 808 0000
(Monday to Friday 09:00 to 21:00)
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Carers UK
Freephone: 0808 808 7777
(Wednesday to Thursday 10:00 to 12:00 and 14:00 to 16:00)
Email: info@carersuk.org
Website: www.carersuk.org

Cancer Help UK
Freephone Helpline: 0808 800 4040
(Monday to Friday 9:00 to 17:00)
Website: www.cancerhelp.org.uk

Cancer Research UK
Website: www.cancerresearchuk.org
National Library for Health
(covers all aspects of health, illness and treatments)
Website: www.library.nhs.uk

NHS Direct
Telephone: 0845 4647 (available 24 hours)
Website: www.nhsdirect.nhs.uk

Patient UK
(comprehensive, free and up-to-date health information)
Website: www.patient.co.uk
Space for notes and questions