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 having radiotherapy treatment to a limb (arm or leg) for a bone or soft tissue sarcoma. The booklet explains the side effects your child may experience during and after treatment, and how best to cope with them.

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 red, flaky and itchy during the radiotherapy treatment. This is a normal reaction. Your child may get some dry peeling of the skin in the treatment area. Some children who are having their thighs treated may experience peeling of the skin that is “weeping”, which can be very sore. If your child’s skin peels and is “weeping” he/she will be referred to the radiotherapy nurses for appropriate care.

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. Pat the skin dry with a soft towel. **Do not vigorously rub the skin in the treatment area.**

Aqueous cream, which you will be given at the start of treatment, may be applied to the treated skin. This is a simple, unperfumed moisturising cream which 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 in the treatment area becomes too tender and sore do not use aqueous cream. Your child will be referred to the nurses for advice.

**Do not use any other talcs, creams or lotions in the area being treated unless advised by a member of staff.**

Avoid exposing the skin in the treatment area to strong sunlight or extreme temperature changes during and after treatment. 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.

**Hair loss**
Your child will only lose hair in the area being treated. Hair loss will occur approximately in two to three weeks into treatment. Hair might not grow back completely in the areas which have had a very high dose of radiation. Your child’s doctor will advise you if the lost hair is unlikely to regrow.

**Swelling of the limb**
Your child may experience swelling and tenderness in their limb as treatment progresses. This is normal. It is due to inflammation of the tissues caused by the radiotherapy. This will settle after treatment has finished, but in a few patients this may persist.

**Stiffness**
Your child may experience stiffness in their limb. This is a normal reaction. This is due to the effects of the radiotherapy causing slight swelling on the underlying muscle tissue.
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. Many children do experience a loss of appetite. This may be due to a number of factors such as anxiety about unfamiliar surroundings or side effects of radiation or chemotherapy 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 our leaflet “Eating hints for patients”.

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”.

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 accurately predict and, unfortunately, when they do occur they are usually 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**
Radiation therapy will affect the growth of bones and soft tissues in the treated limb. In younger children this will mean that the treated limb will be smaller, thinner or less muscular than the untreated limb. Your child will be regularly monitored from diagnosis by an endocrinologist (a specialist) in a growth clinic and growth hormone will be given if the growth rate slows.

If you are concerned please speak to the radiotherapy doctors.

**Osteopaenia (low bone density)**
Low bone density can occur for a number of reasons, including poor immobilisation, poor nutrition, low calcium levels, steroid therapy, as well as radiotherapy to the skeleton. Weight bearing exercise, eating a healthy diet and leading a healthy lifestyle can all prevent this, along with timely hormone replacement therapy. Your child will be screened for this in the endocrine clinic as he/she grows up.

**Swelling of the limb (lymphoedema)**
There is a possibility that the limb below the level of surgery may be inclined to swell in the future. This is due to the build up of lymphatic fluid (a clear fluid that helps fight infection and disease), which flows through lymphatic vessels. The lymphatic vessels are part of the lymphatic system, which helps to fight infection and maintains a balance of fluids in the body. Radiotherapy significantly increases the risk of swelling, especially in the leg, by causing scar tissue to form.
which interrupts the normal flow of the lymphatic fluid. The chances of this happening depend on several factors—not only the size and position of the tumour and the extent of your child's surgery, but on how much of your child's limb is treated. The radiotherapy doctors will warn you if it is considered a significant risk for your child. Prolonged standing and being overweight will increase this tendency to swelling.

**Fibrosis**
Some children may experience long-term fibrosis or thickening of the muscle and tissue that has been treated. The skin in the area being treated may feel “leathery” due to a loss of elasticity and suppleness. Regular stretching exercises, good skin care, the use of water-based moisturisers and sun avoidance can minimise these effects.

**Fracture**
there is a small risk that the bone in the area treated will be at an increased risk of fracture in later years and there may be problems with healing.

**Second malignancy**
Very rarely, children who have received treatment for one particular tumour may develop another type of tumour 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 four weeks time. This will either be at Great Ormond Street Hospital or University College London Hospital.

The side effects your child will 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 the 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 the following 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
**National:**

**ROH BTS**
A support service offering emotional and practical help to patients and families wherever they are treated.
Jenny Richardson: 0158 485 6209
Pat Rice: 0121 422 8273

**Sarcoma UK**
A website and newsletter offering further links and advice to patients and their families.
Telephone: 0158 487 8497
Email: info@sarcomauk.org
Website: www.sarcomauk.org

**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

**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

Teens Unite
Telephone: 0199 244 0091
E-mail: info@teensunitefightingcancer.org
Website: teensunitefightingcancer.org

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