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 to the head, mouth and neck. There are several different tumours that may affect the head and neck. For some, radiotherapy is used alone and in others chemotherapy may also be used. The booklet explains the side effects your child may experience during and after radiotherapy 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. The side effects will depend on which part of his/her face, mouth and neck is being treated and what dose of radiotherapy is given.

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.

There are side effects occurring during treatment, some happening soon after treatment, and some appearing months or years after radiotherapy.

Skin changes
The skin in the area being treated can become red, flaky and itchy during treatment. There may be some dry peeling of the skin, but some children may experience peeling of the skin that is “weeping”, which can be very sore. The skin behind the ear or the ear itself (if this is included in the treatment area), can become very sore and moist. If your child’s skin peels and is “weeping”, he/she will be referred to the radiotherapy nurses.

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 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. Ensure your
child wears a hat/cap at all times when outside to protect the head and neck. It may also be helpful for your child to wear a silk scarf to protect his/her neck when outside. It is advisable that your child wears loose clothing around the neck such as T-shirts or polo shirts. Wherever possible, let the area being treated get as much air as possible.

Radiotherapy causes changes to the skin. This makes it more sensitive to the sun. Avoid exposing the skin in the treatment area to strong sunlight or extreme temperature changes during and after treatment. The skin in the treated area will be especially sensitive for the first twelve months after treatment. If outside during strong sunlight ensure your child wears a hat/cap to protect their head and neck. 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.

If there is hair in the area being treated this will fall out. Hair loss in the area being treated usually occurs approximately two to three weeks into treatment. Hair loss may be temporary or permanent. Please ask your child’s radiotherapy doctor if the lost hair is likely to regrow.

**Effects on the mouth**
The cells lining the insides of the mouth and neck are very sensitive to radiation. Common problems your child may experience during treatment include:

- Soreness due to inflammation of the tissues
- Dryness of the mouth due to radiation effects on the salivary glands. This also leads to taste changes and difficulty in swallowing.
- Infections due to lack of saliva. This can be seen as white patches on the inner surface of the cheeks or covering the tongue (oral thrush)
- The production of thick saliva or mucus which may lead to nausea or vomiting
Please ask for the leaflet “Mouth care during radiotherapy” which provides information and advice on how to look after your child’s mouth during their radiotherapy treatment. Do not hesitate to ask for help and further advice from the staff in the radiotherapy department.

**Eating and drinking**

It is important that your child eats a well balanced diet during his/her radiotherapy treatment. If your child is having treatment to the mouth and neck he/she may have difficulty chewing and swallowing food as the inside of his/her mouth and throat may be sore. Some children may require oral medication to assist with swallowing. In each case he/she will need to see the Paediatric Dietitian and the Speech and Language Therapist. Both will advise you and your child about swallowing and nutrition issues.

Your child may also experience a change in taste which will make eating and drinking less enjoyable, as well as reduce his/her appetite. 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.

It is important that your child drinks plenty of fluids, between one to two litres a day. This can include water, squash, or hot drinks. This will vary depending upon their individual needs. You will be advised accordingly by the team members.

Please ask for a copy of the leaflet “Coping with a sore mouth” which provides advice on eating during radiotherapy. 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.

**Effects on the voice**

If your child is having radiotherapy to the throat his/her voice may become hoarse. This can worsen and some children may temporarily lose their voice. It is advisable to allow your child to rest his/her voice as much as possible during treatment. Do not allow your child to strain his/her voice to make themselves heard. When the treatment has
finished it may be a few weeks before his/her voice starts to recover, and in some cases it may always remain husky. If your child’s voice does not improve, he/she will need to see the Speech and Language Therapist for voice therapy.

**Hearing problems**
Swelling due to the radiotherapy can cause fluid to accumulate in the ear, if the ears are in, or near, the area being treated. This may cause your child to experience some temporary hearing difficulties.

Some children may lose the ability to hear high tones, particularly after receiving certain chemotherapy drugs. Following treatment your child’s hearing will be regularly monitored.

**Tiredness**
The treatment visits may make your child feel more tired and fatigued than usual. It may even continue for several weeks after the radiotherapy has finished. This is a normal reaction. Many children undergoing radiotherapy experience some degree of fatigue during their treatment. Allow your child to get plenty of rest. Let them set their own pace.

However, many children do not have a problem with tiredness and should be encouraged to lead as normal a life as possible. If you are worried about anything, do not hesitate to ask for help. We are here to help you. Please ask for a copy of the 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 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:

Skin changes
Radiotherapy may result in scarring of the skin and its underlying structures. This gradually turns soft, supple skin hard and “woody”. It is more likely to happen if your child has previously undergone surgery or chemotherapy. Good skin care, the use of water based moisturisers and sun avoidance can minimise these side effects.

Loss of taste sensation
Loss of taste can be a distressing symptom, but this usually recovers within three to four months after the end of radiotherapy. However, a small percentage of children may have a permanent loss of taste or altered taste perception.

Dental decay
Radiotherapy may cause tooth decay and discoloration due to reduction in blood supply. It may also cause gum shrinkage causing further dental problems. If your child requires dental treatment, be sure to inform the dentist that he/she has received radiotherapy to the mouth. Regular dental checks are important to minimise these problems.

Dry mouth
The radiation damages the salivary glands which produce saliva, therefore reducing the amount of saliva made. Some children may experience the production of thick saliva/mucus which can be distressing, as it can lead to nausea and vomiting. Saliva production improves over the months following treatment, but it may not return to normal entirely. There are artificial saliva replacements available from the chemist. Please ask your child’s doctor or GP about their use.
Oral infections
Following radiotherapy your child may be more susceptible to fungal infections such as thrush within the mouth due to a lack of saliva. This will be made worse by poor dental hygiene. You or your child may notice white areas on their tongue and/or inside their cheeks, and mouth ulcers. Please contact your child’s GP, who will prescribe a course of antibiotics.

Difficulty opening the mouth (called trismus)
Your child may find it difficult to open his/her mouth wide if they have had radiotherapy to areas such as the jaw, tongue or tonsils. This may appear three to six months following radiotherapy. It is due to the tightening of the muscles which open the mouth.

The Speech and Language Therapist will provide your child with stretching exercises to undertake to relieve this condition, or if they are started early, to prevent it.

Decreased thyroid function
If your child has had radiotherapy to the neck this can affect the thyroid gland. It may become underactive, overactive (very rarely), or tend to form lumps many years after treatment has finished. Your child will be monitored through regular blood tests and if a dysfunction is detected, it can easily be treated.

Swelling
Swelling of the neck, especially under your child’s chin, may persist for several weeks or even months after radiotherapy. It is often worse in the morning and feels like a lump under the chin. This condition is known as “dewlap” and is a recognised side effect of treatment.

Although “dewlap” rarely causes any problems, many parents are worried that the swelling might represent a recurrence. If you are anxious, contact your child’s specialist nurse or doctor. This condition usually resolves six months to a year after treatment.
Cataracts
The development of mistiness of the lenses of the eye can occur because of unavoidable radiation to the eye. This usually develops five to six years after treatment. In many cases this will not have an effect on your child’s vision. However, in a small number of children they may require surgery to remove the cataract. Following treatment, your child will have regular checks.

Growth
Radiation may affect the growth of the vertebral bodies (neck bones) in the radiation field. There might be some underdevelopment of these, with some loss of height. However, it is unlikely to be severe unless your child is very young.

For some tumours we have to include the pituitary gland (at the base of the brain). This means that it may not produce enough growth hormone as your child develops, particularly in puberty. Your child’s growth and puberty will be monitored closely during and after treatment by endocrinologists (doctors specialising in glands). Tests for growth hormone deficiency will be performed. With early growth hormone therapy, children should achieve their full height potential.

Bone and muscle growth
Radiation will also affect the development of bone and muscles in the area treated. In a child who is still growing this may mean that the bones and muscle in the treated area will be smaller and so look different.

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.

Post-radiotherapy dental care
Following radiotherapy to the mouth, especially if saliva production has been reduced, it is essential that your child’s teeth are cleaned regularly and that regular dental check-ups are performed.

The dentist must be told about the radiotherapy treatment. This is important if your child ever needs teeth removed.

Please ask for the leaflet “Care of the mouth after radiotherapy” which provides information and advice on how to deal with these side effects. If you have any worries or questions please do not hesitate to ask for help.
After your child’s radiotherapy has finished

Once your child’s radiotherapy treatment has finished you will be given a follow-up appointment to see the doctor in about four weeks time at Great Ormond Street Hospital or University College London Hospital. If your child has been receiving regular nursing care during their treatment they will be seen in one or two weeks time in the head and neck symptom clinic. A letter will be sent to your local district nurse and GP telling them what treatment your child has received, what medication they are on and what dressings, if appropriate, are needed.

The side effects your child has experienced will continue even after radiotherapy treatment has finished. Your child will still have to follow the skin and mouth care regimes for about 10 to 14 days post radiotherapy. However, most of these side effects should resolve within three to four weeks after treatment has finished. If you have any worries please contact the radiotherapy department, the nursing staff or the Macmillan information and support radiographer.

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
bleep1138/2075
National:
Changing Faces
Telephone: 020 7706 4232
Monday to Friday 09:00 to 17:00
Email: info@changingfaces.co.uk
Website: www.changingfaces.co.uk

Let’s Face It
London Office: 020 8952 4990
Christine Piff: 0125 287 9630

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

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