Radiotherapy to the whole Central Nervous System
Radiotherapy Department
Paediatric information series
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.
**Introduction**

This booklet has been written for parents and carers whose child is having radiotherapy treatment to the brain and spine for Primitive Neuroectodermal Tumour (PNET), Germinoma, or some other condition. The treatment may also be referred to as whole central nervous system (CNS) or cranio-spinal radiotherapy. 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. 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. The skin behind the ear or the ear itself (if this is included in the treatment field) can become very sore and moist. 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 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, and that they wear a top to protect the skin on the back.

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 25–40 or more) in strong sunlight.

**Hair loss**

Some children may have already experienced hair loss due to chemotherapy, but some may still have their hair when they start radiotherapy. Hair loss usually occurs after three weeks of radiotherapy treatment, and this will be total. The hair usually starts to grow back about three months after treatment. The new growth will often be slightly different in colour and texture. His/her hair might not grow back completely in the areas which have had a very high dose of radiation. This is usually the area at the back of the head. The doctors will advise you about this.

To help hair grow back, it is vitally important that all your child’s hormone and iron levels are adequate. These can be checked and treatment prescribed by endocrinologists (doctors specialising in glands) who support the service.

You may wash your child’s hair gently, using warm water. Use a mild non-perfumed shampoo such as a baby shampoo and limit hair washing to two or three times a week. When drying, use a soft towel and gently pat the scalp dry. You may also use a hair dryer on a cool setting or leave the hair to dry naturally. Brush and comb the hair gently using a baby (or other soft) brush or a wide rounded-toothed comb. Losing hair can be very distressing for children, particularly older children and teenagers. If required, wigs are available on prescription
(and free of charge for patients having radiotherapy and/or chemotherapy) through the NHS. If you and your child wish to discuss wigs with the hair specialist, the radiographers treating you, the nurses or the play specialist will be able to give you further information.

Alternatively, some children choose not to wear a wig, except on certain occasions. They may choose a fashionable and practical hat, cap or scarf.

**Feeling sick (nausea)**
Following a treatment session some children may feel sick (nauseated) and vomit following a treatment session. Your child may have been prescribed regular anti-sickness medication to take during treatment. However, if they are still experiencing symptoms please speak to a member of staff who can refer you to the doctor for further medication. Please ask for a copy of the leaflet “Coping with nausea”.

**Headaches**
The treatment can cause the treated area in the head to swell slightly and so your child may develop signs of raised intracranial pressure which can include headaches, nausea, vomiting or double vision. This is usually for a short period of time, but it is important to inform a member of staff if your child is experiencing such symptoms as a small dose of steroids can reduce the swelling and may be required. If your child has a VP shunt (a tube draining fluid from the brain to the heart or gut) and is experiencing headaches, it is important to seek advice from the doctor or the specialist nurse. It may be an indication of a blocked shunt.

**Diarrhoea**
Some children may experience loose bowel motions during their radiotherapy treatment. This is due to the radiation to the lower part of the spine irritating the bowel. If your child experiences this symptom please inform a member of staff as they can advise you about anti-diarrhoeal medication. Your child may also experience pain and/or cramping sensations. It is important that he/she maintain a good fluid intake if this is a problem, between one and two litres a
day. This can include water, squash or hot drinks. Please ask for a copy of the leaflet “Coping with constipation or diarrhoea”.

Sore throat
Your child may begin to experience a sore throat about two to three weeks into radiotherapy. This is because radiation to the top of the spine irritates the throat. He/she may experience discomfort when eating certain foods. Some children may require oral medication to assist with swallowing.

Blood and bone marrow system: radiation to the spine may affect the bone marrow (which makes blood cells) in the vertebrae (spinal bones). The white blood cells (which fight infection) and platelets (which are important for blood clotting) may be affected. Your child’s blood count will tend to fall as radiotherapy treatment progresses. Regular blood tests will be required (two per week when treating the spine). This can either be done at University College London Hospital or via your home care team. If your child requires a transfusion, this will be arranged with T11 Paediatrics (for children under 13) or T12 Adolescents (for children over 13). In a very small number of cases some children may require daily blood counts and parents need to be aware that a low white count or platelet level may cause treatment to be temporarily stopped.

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 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.
Side effects after treatment
As well as side effects that occur during treatment, there may also be side effects of radiotherapy treatment that occur several weeks after the treatment has finished. Please ask your child’s radiotherapy doctor about the chances of such side effects occurring. These include:

Somnolence syndrome
Is described as excessive sleep, drowsiness and lethargy. The majority of children undergoing whole CNS radiotherapy experience some degree of fatigue and drowsiness during their treatment. Allow your child to get plenty of rest. Let him/her set their own pace. However, many children do not have a problem with tiredness and should be helped to lead as normal a life as possible. Returning to school following treatment needs to be carefully managed. A gradual return allows your child to achieve as much as possible without being over-stretched. Your child’s specialist nurse can help with this.

There might be a particularly sleepy spell starting four to six weeks after treatment ends and going on for two to six weeks or even longer. You may notice that your child has a lack of energy and cannot be bothered to do anything. This is a normal reaction to the treatment but the long duration and sometimes the severity of the symptoms can cause parents anxiety. Please ask for 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.

Pre-existing symptoms
Your child may experience an increase in pre-existing neurological symptoms (the symptoms that occurred before diagnosis). These include headaches, nausea, vomiting, double vision and weakness. Do not panic or worry. Contact your child’s specialist nurse, neurology doctor, radiotherapy doctor or GP if you notice any of the symptoms
listed. Since the brain lacks an effective lymph system, dead tumour cells are cleared away very slowly. A rapid build-up of dead cells can lead to swelling which might produce a temporary increase of symptoms.

These reactions are usually treated with steroids and most of them go away with minimal treatment. However, they can become life-threatening if they are not treated properly. Therefore, it is important for your child’s doctors to be aware if he/she experiences these reactions so they can monitor his/her progress and adjust the steroid medications, if necessary.

**Steroids**
Steroids are drugs used to reduce the swelling associated with brain tumours and their treatment. They can temporarily relieve symptoms, improve your child’s neurological status and make them feel better. However, steroid medications in the doses used have their own important side effects. They will tend to make your child hungry, gain weight, develop acne, develop a puffy “rounded” face, be prone to mood swings, and be potentially more vulnerable to infections. Please ask your child’s doctor for the relevant steroid card and leaflet.

**Steroids should never be stopped suddenly.** Do not change your child’s dose unless the doctor tells you to do so, and when the steroids are stopped, they must be gradually withdrawn on a schedule prescribed by the doctor.
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**
Young children will not grow as tall as they would have been. Radiation to the brain affects the pituitary gland (which produces growth and other hormones). Radiation to the spine affects the growth and strength of the vertebrae (the bones of the spine). There might be some under development of these bones, with some loss of height. Your child will be regularly monitored from diagnosis by an endocrinologist in a growth clinic, and growth hormone will be given if the growth rate slows and a deficiency of growth hormone is confirmed on testing. However, it is likely that the youngest children at diagnosis will be up to three inches shorter as adults. Early treatment can help limit this, but in some cases growth hormone may be required in adult life.

**Early (Precocious) puberty**
The pituitary gland also controls puberty development. The presence of a brain tumour and radiotherapy to the brain may make puberty start and finish earlier, limiting the time available for growth. Endocrinologists (doctors specialising in glands) will closely monitor your child during and after treatment. They will deal with any issues that arise.

**Thyroid gland**
Thyroid gland function can be affected by the radiotherapy or thyroid hormone from the pituitary 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.
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.

Fertility
Girls fertility is rarely affected from radiation to the spine field scattering to the ovaries. The risk in boys is even less as their testicles are further away from the treatment field. Post pubertal boys receiving chemotherapy and radiotherapy should be referred to the endocrinologists for a discussion about sperm banking.

Sexual maturation is less usually affected except in girls, who may experience a delay or arrest in puberty or the onset of menarche (periods). This is much more likely after chemotherapy. The doctors will discuss this with you and your child.

Schooling and learning
It is possible for the tumour, surgery, chemotherapy and radiotherapy to affect learning ability, especially when the child is very young (up to seven years of age). There may be a small but significant decline in intelligence points (IQ) and weaknesses in number skills, spelling and in the processing speed of acquiring new information and skills. Your child will be closely assessed by clinical psychologists and his/her teachers should be informed about the potential problems that may occur. Most children are educated in mainstream schools, but some may require one-to-one teaching to address a special need and prevent a further decline in IQ.

This will require close liaison between yourselves as parents, the psychologists, the hospital, the specialist nurse and the school. Most children achieve independent and fulfilled adult lives.
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 in later years. Fortunately cataract surgery today is very straightforward and successful.

Following treatment, your child will have regular visual checks.

Cavernomas
Following radiotherapy to the brain, some children may develop a small benign abnormality. These abnormal areas in the brain are due to a small tangle of blood vessels and are called cavernous haemangiomas, or cavernomas for short. In most cases they cause no problems, but are detected on a routine follow-up MRI scan. Very occasionally cavernomas may be discovered on a scan performed to investigate symptoms which might be due to tumour recurrence, but in fact have been caused by the small abnormal blood vessels bleeding.

Cavernomas may appear some months or many years after radiotherapy, typically after about three years. The risk of developing a troublesome cavernoma is very low, only about one per cent.

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 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:
British Brain and Spine Foundation “Headstrong” Children’s Information Programme
Freephone: 0808 808 1000
Telephone: 020 7793 5900
Email: headstrong@brainandspine.org.uk
Website: www.headstrongkids.org.uk

Brain Tumour Action
Main/Befriender Helpline: 0131 446 0236
Other telephone: 0150 643 6164 (evenings and weekends)
Website: www.braintumouraction.org.uk
Brain Tumour UK
Telephone: 0845 450 0386
Email: enquiries@ukbts.org.uk
Website: www.braintumour.org.uk

British Brain Tumour Association (National Information Line)
Telephone: 0151 929 3229
Fax: 0151 929 3229
(10:00 to 16:00)

Samantha Dickson Brain Tumour Trust
Telephone: 0845 130 9733
E-mail: enquiries@sdbtt.co.uk
Website: www.braintumourtrust.co.uk

Nottingham Children’s Brain Tumour Research Centre
Telephone: 0115 951 3724
Email: emma.pearson@nottingham.ac.uk
Website: www.cbtrc.org

CLIC Sargent
Freephone helpline: 0800 197 0068
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
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
Email: 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