



Total body irradiation (TBI) in children and young people

An information guide for patients, parents and carers

The purpose of this guide is to help you understand more about total body irradiation (TBI) in children and young people with cancer.

Information in this guide should be used to support professional advice specific to your/your child's diagnosis. If you have any questions, it is important to ask your medical team.

What is total body irradiation (TBI)?

TBI means treatment of the whole body with radiotherapy. It is used as part of the conditioning therapy (preparation treatment) for some patients who need a stem cell transplant (SCT). The aim of this radiotherapy is to destroy any remaining cancer cells in the body and suppress the immune system so that it cannot fight against the new donor stem cells.

Planning your total body irradiation (TBI)

Your stem cell transplant (SCT) consultant and team will discuss TBI and when treatment will start. About 3-4 weeks before you/your child is admitted for SCT, you will be invited to attend a planning appointment with your local radiotherapy department.

You will meet the radiotherapy team who will care for you/your child during this treatment. Some patients may have to go to a different hospital to where they will have their SCT. Your radiotherapy team will explain how their centre works and arrange your/your child's care.

Your radiotherapy consultant (clinical oncologist) will talk to you about TBI, answer any questions that you may have, and take consent for this treatment.

The planning of your/your child's TBI may include a CT scan (computerised tomography: a high-resolution scan) or X-ray and a test dose in the radiotherapy room.

Before the CT scan or X-ray, females aged 12 years and above will need to take a pregnancy test and be advised on taking precautions to avoid becoming pregnant.

Following the CT scan, a small permanent ink mark may be made on your/your child's chest. This is very small and will look like a freckle. This mark is used by the radiographers during treatment.

The radiotherapy test dose is a practice run of the TBI treatment, where a small dose of radiation is given. The test dose can take up to an hour to complete. The team will make sure that you/your child is in the correct position, and then give short exposure(s) of radiation. This helps to plan the correct dose for the TBI treatment.

The treatment position may involve you/your child lying on your/their back or sitting in a chair with arms

across your/their chest. Occasionally, young children need sedation or a general anaesthetic for planning and TBI. Each unit has a health play specialist who will prepare and support younger children throughout the whole process.

Having TBI

The number of treatment sessions you/your child needs will be discussed with you. It can be between one and eight treatments. If it is more than one, you may be given two treatments per day, with at least six hours in between.

The TBI involves you/your child lying or sitting very still. The radiographers will put you/your child in the correct position and check that you/they are comfortable. Treatment is given to each side of the body (right and left). You/your child will be lined up with the machine and, once everything is in the correct position and you/they are ok, the team will leave the room. The treatment takes about ten minutes for each side.

The treatment does not hurt and there may be a buzzing noise when the machine switches on. The radiographers watch all the time on a screen outside the treatment room and they can speak to you/your child via an intercom. If you/your child is uncomfortable or upset at any time, the treatment can be paused and the radiographers will come into the room to help. You/your child can listen to your/their own music to help with relaxation.

Once TBI is completed, you/your child will return to the SCT room/hospital and continue your/their care.

Side effects of TBI

Side effects can vary and it is important to remember that not all patients will get all of them. Some side effects happen during treatment and others may happen months or years afterwards. Your SCT team will have discussed these as part of the consent for SCT.

Common side effects during treatment with TBI

Effects on skin

Towards the end of radiotherapy treatment, and the following week, your/your child's skin may be red, sore,

sensitive, and warm to the touch. It may also become dry. These skin reactions are normal, but it is important to take extra care of your/your child's skin:

- wash skin gently using mild, unperfumed soap/oil and warm water
- avoid soaking in a hot bath
- pat skin dry using a soft towel
- avoid using perfume, talcum powder, deodorants or creams containing sodium lauryl sulphate (SLS)
- avoid shaving
- avoid tight and restrictive clothing
- avoid exposure to sunshine
- avoid exposure to hot and cold temperatures (for example, food, drinks, bath water or the weather)
- use moisturising creams and washes (emollients) that don't contain SLS
- avoid metal-based barrier creams such as metanium or sudocrem

Your SCT team will give you more advice about looking after your/your child's skin.

Hair loss

You/your child may have already lost hair due to previous chemotherapy. If this has not been the case, the TBI and chemotherapy will cause hair loss. This happens about 2-3 weeks after the first treatment. It does not hurt when hair falls out, but it can be very distressing. Your medical team will talk to you about having a wig if needed.

Nausea and vomiting (feeling sick and sickness)

TBI can cause nausea and vomiting and anti-sickness drugs will be given to help with this.

Diarrhoea, wind (flatulence) and tummy (abdominal) pain

TBI can cause diarrhoea, wind and tummy pain and pain relief will be given to help with this.

Sore, dry mouth

Your/your child's mouth may become sore and lips can become dry, which can last up to three months. Good mouth care and regular drinks can help to relieve this. Pain relief can be given and if your/your child's mouth is dry you/they can have artificial saliva.

A small number of patients have swollen or inflamed salivary glands. This usually lasts for 1-3 days. Pain relief is given to help with this.

Loss of appetite

Not wanting to eat may be due to feeling sick and having tummy pain. You/your child will be seen regularly by a dietitian who will advise on food and supplements.

Low white cells, platelets and red blood cells (bone marrow suppression)

Your/your child's original bone marrow cells will be destroyed during TBI. This means you/they will have low counts of platelets, white cells and red blood cells. This is called bone marrow suppression. You/your child will receive blood and platelet transfusions and protective antibiotics.

Possible side effects after treatment with TBI**Sleepiness (somnolence syndrome)**

Most people who have had TBI experience excessive sleeping, drowsiness and lethargy. It is important to let yourself/your child rest when needed.

This kind of sleepiness usually starts 4-6 weeks after TBI treatment, and can last up to 2 weeks. You/your child may have no energy. Some children and young people may sleep so much that they need to be woken up to drink and eat. It is very important at this time to make sure that you/your child are drinking enough. If you have any concerns, please discuss these with your SCT team and the dietitian.

Infertility and pregnancy

Unfortunately, the likelihood of infertility is high following TBI treatment which affects the ability to become pregnant or father a child naturally. Your SCT team will discuss this with you more.

Altered hormone levels and thyroid function

TBI may affect the function of some of the glands that produce hormones. Your SCT consultant may refer you/your child to a hormone specialist (endocrinologist). This will most likely happen in a long-term follow-up clinic.

Growth and development

The pituitary gland (in the brain) may be affected by the radiation so that it is unable to produce enough growth hormone.

When young children are treated with radiotherapy it may affect their future learning ability, and they may find it difficult to learn new information and skills. The

clinical psychologist within the SCT unit will be able to do assessments before and after TBI to help detect any problems so that appropriate support can be planned.

Clouding of the eye lens (cataracts)

Cataracts occur in the lenses of the eyes and can cause vision to be blurred. They can occur from around three years after TBI treatment. Your/your child's eyesight should be tested yearly by an optician. If you/your child has any problems, you/they will be referred to an ophthalmologist (eye specialist).

Lung changes

TBI may affect the lungs. If any problems occur your SCT team may want to send you/your child for lung tests. It is important to reduce the risk of having problems by not smoking.

Skin

Skin may be dry for some time. Your SCT team will advise you on moisturising (emollient) creams to help with this. It is important to keep your/your child's skin well moisturised if it is dry. To prevent further skin damage it is important to take care of your/your child's skin in the sun – use a high-factor sun cream and avoid sunburn.

Risk of other cancers

TBI can increase cancer risk later in life. To reduce this risk it is important to have a healthy lifestyle. Some of the things that you/your child can do to support a healthy lifestyle are take care in the sun, maintain a healthy weight, exercise regularly, and avoid smoking. Early detection of any possible problems is important. In the future, if you/your child are concerned about possible other cancers, you should discuss these at your long-term follow-up clinic or visit your GP.

Psychological effects

Having a SCT and TBI can be a very emotional and stressful time for you/your child as well as family and friends. You and your family may have fears and concerns related to changes in your/your child's body, uncertainty about the future and separation from family and friends. It is important to know that there is help available if needed, so please speak to your SCT team if you are worried.

TBI is a critical part of treatment and your team believe it offers the best chance of a cure.

It is difficult to predict how each person will be affected by TBI but it is important that you understand the potential effects before you/your child starts treatment.

You may feel worried, but please remember you can discuss your fears and concerns with your SCT team.



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USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG)

publishes a variety of free resources to order or download www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer. www.macmillan.org.uk



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Patient Information Forum

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70085 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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