



Great Ormond Street Hospital for Children NHS Trust: Information for Families

# Chemotherapy for childhood brain and spinal cord tumours

**This leaflet explains about chemotherapy for childhood brain and spinal cord tumours and what to expect when your child has treatment. It should be read alongside our main booklet *Childhood brain and spinal cord tumours*. If you have any questions about the information in this leaflet, please ask your clinical nurse specialist.**

## What is chemotherapy?

Chemotherapy is the term given to the treatment of tumours using strong drugs called cytotoxics (meaning cell poisons). Although chemotherapy is the main treatment for many malignant diseases such as leukaemia, it is a relatively new treatment for children with brain tumours. This is because it is only in the last few years that combinations of drugs have been developed that have been shown to have some effect in destroying CNS tumour cells. Much still depends on the tumour type but a wider use of chemotherapy is now being incorporated into treatment management.

The doctors will advise you as to whether chemotherapy is recommended and, if so, at what stage of your child's treatment plan. You will also be informed as to what drugs will be used. There are a variety of drugs that can be used either as single agents or in combinations of several drugs. Treatment therefore varies between one child and another.

## How is chemotherapy given?

Chemotherapy can be given in tablet form, but it is usually administered by injection into the blood stream. In preparation for chemotherapy, children will have a small surgical procedure to insert a long-term narrow tube, which is threaded into a major blood vessel. This provides easy access to the blood system for giving the chemotherapy and for taking blood samples, and protects the child from regular injections. There are two types of access most commonly used:

- A central venous catheter, which is a length of tubing that leaves the body at the chest. When it is not being used for treatment purposes it is discreetly tucked away close to the skin and protected with a small dressing
- An implantable port, which lies underneath the skin. It is seen as a small lump under the skin's surface and is also usually on the chest.

Both are fitted during a small operation using a general anaesthetic. The ward staff will prepare you and your child for this procedure and will later teach you the necessary care of the catheter or port. This will remain in place until all the chemotherapy is finished.



Depending on the treatment regime your child is prescribed, he or she will either be admitted to the ward for several days every two to three weeks or will receive treatment as a day-case in hospital. The length of chemotherapy treatment varies enormously, from between approximately three months to 12 months. These variations in treatment depend on many factors including the type of tumour involved, the child's age, the amount of surgical removal achieved, and the general condition of the child's health.

## Shared care

Shared care will usually involve your family doctor (GP), a paediatric oncology shared care unit (POSCU), which is based at your local district general hospital (DGH), paediatric community team (PCN) and the specialist centre involved in your child's treatment.

The role of your POSCU is to provide medical and nursing support if your child has an episode of febrile neutropenia (a temperature with a low white count) and to ensure that your child receives blood product support. Wherever possible, your POSCU will also be involved in giving parts of the chemotherapy regime and will share your child's follow-up care after treatment has been completed.

We share care with many different centres, and every centre may do procedures differently. This is not to say that they are wrong. Local practice and policy can and does differ, however we do work closely with shared care centre to agree best practice.

## Side effects of chemotherapy

Chemotherapy temporarily damages healthy cells within the body at the same time as it is hopefully destroying the tumour cells permanently. Chemotherapy can, however, cause side-effects within many areas of the body, as opposed to the localised areas affected by radiotherapy. This is because it is administered into the blood stream, and therefore travels around the whole body.

Different drugs cause different side effects. The list below is a general list, your child may not experience all of these and the intensity varies from one child to another. The medical team will describe the specific drugs being used and will explain the side effects that your child may develop. In addition, you will receive information sheets detailing the side effects from each medication before you sign consent for treatment.

**Nausea and vomiting** – This usually occurs at the time the chemotherapy drugs are given or for a few days afterwards and is especially common with the drug cisplatin. Anti-sickness medication will be given to minimise this problem.

**Loss of appetite** – Chemotherapy may make your child feel nauseous or affect the lining of the gut so that he or she does not want to eat. It is not uncommon for a child to lose weight on treatment and therefore your child's weight will be closely monitored. A dietician will be able to advise you. Some children need to be fed via a nasogastric tube (a tube passed from the nose into the stomach)



or gastrostomy tube (a tube passed directly into the stomach during a small operation). Neither of these tubes is permanent and they can be removed once treatment is completed and your child has regained weight.

**Altered taste** - Some children complain of a strange, metallic taste as chemotherapy is given. This tends to be temporary.

**Hair loss** – This mainly affects the hair on the head but occasionally other parts of the body can also be affected such as eyebrows (and pubic hair in older children). Hair usually falls out a week or two after the relevant drugs are given and re-grows in a few months from the completion of treatment.

**Bone marrow suppression** - As with radiotherapy, chemotherapy can affect the production of cells in the bone marrow causing their numbers to fall. The three major groups of blood cells are white blood cells, red blood cells and platelets. Before your child is discharged from hospital you will be given details of when blood tests will need to be taken. This can usually be done at home by your community nurses or at a hospital locally. You will be informed of any abnormal counts to ensure that you can provide your child with the necessary care. The symptoms and treatment depend on which group are affected:

**Low numbers of white blood cells**

– White cells help fight against infection. Thus a low white cell count will increase the child's risk of becoming ill with an infection. You will be advised about the care of your

child and what signs to look out for. Sometimes an infection will require hospital admission for treatment with intravenous (via a drip) antibiotics. A low white cell count will delay the next course of chemotherapy, as this will not be given until the count has improved. A delay for this reason will not be detrimental to your child's treatment.

**Low numbers of red blood cells** - These carry oxygen around the body. A fall in the red cell count results in anaemia. Your child will be tired and lethargic and may look pale. He or she may be nauseated and lose his or her appetite. Rest is encouraged and an iron-rich diet. If the cell count is very low a transfusion of blood will be given.

**Low numbers of platelets** – These are involved in the blood clotting process, preventing excessive bleeding. A low platelet count will result in the child bruising more easily than normal, and bleeding for longer if injured. A very low count will be treated with a transfusion of platelets.

**Numbness and tingling** – Your child may complain of aches and pains in his or her legs. This is a reasonably common side effect of vincristine. You may initially notice that your child is clumsier than usual or has more difficulty walking. In younger children the eyelids may droop. It is important to report any changes to your doctor. These are temporary side effects, which may require a reduction in the dose and improves with time.



**Jaw pain** - Your child may also complain of jaw pain or seem to have more difficulty chewing and swallowing. Again, this is a temporary side effect of vincristine, caused by an interruption to the cranial nerves that run along the side of the face.

**Kidneys problems** - Certain chemotherapy drugs can change how the kidneys function over time but fortunately these problems are not severe. Your child will have a kidney function test (GFR - Glomerular Filtration Rate) before treatment starts and then at regular intervals throughout treatment. This involves a series of blood tests taken over the course of a day and measures how effectively the kidneys are working.

**Hearing** – Certain chemotherapy drugs can also affect hearing. Often hearing loss involves high-pitched sounds and is irreversible. This will be closely monitored and your child will have a hearing test at the start of and during treatment. If there is a concern with hearing the dose of chemotherapy can be reduced to prevent further problems.

**Allergic reactions** – Some children receiving chemotherapy may have an allergic reaction, which may be

mild or severe. Signs of a mild allergic reaction include: skin rash, itching, high temperature, shivering, and redness of face, dizziness or headache. If you see any of these signs, please report them to a nurse or doctor. A severe allergic reaction is rare. Signs of a severe reaction include the above as well as shortness of breath or chest pain. Should you child show signs of a severe reaction, call a nurse or doctor immediately. If your child has a severe reaction at home, call an ambulance immediately. If your child has a severe reaction, treatment is likely to be changed.

The medical team will discuss other side effects with you.

#### Notes

**If you have any questions, please  
telephone the symptom care team on  
020 7829 8678**

Compiled by the neuro-oncology team in collaboration with the Child and Family Information Group  
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