

Yorkshire Regional Centre for Paediatric and
Adolescent Oncology and Haematology

Chemotherapy side-effects and protection from infection

Information for patients, parents
and carers



Leeds children's
hospital

This information booklet has been written to provide you with information regarding chemotherapy treatment and to guide you in caring for your child at home. Information about re-admission and continuing treatment is also included.

Going home is often a daunting time for families and you may find that you feel anxious and lack confidence. This is normal and staff are always prepared to listen to your worries and answer any questions that you may have.

What is Chemotherapy

Chemotherapy means to treat with drugs, and most of the drugs that are used to treat cancer are very powerful. Chemotherapy is very effective at 'killing' cancer cells, which are cells which divide quickly. However, it can't tell the difference between cancer cells and the 'normal' healthy cells that we all have in our bodies. Cancer cells are very similar to normal cells, and some of those normal cells get damaged during treatment. This leads to some of the side effects we will explain in this leaflet.

During treatment we monitor children and young people closely, we watch for any side-effects, and we do tests to check whether any damage is taking place. If we find any problems what we do next depends on how serious those problems are. We may change a drug, reduce the dose or sometimes we may decide we have to accept some side effects as the cost of curing the cancer. We will always explain this to you and agree any actions with you.

Blood tests

One of the most common tests that we do is to check the blood count; this is because most chemotherapy affects the cells in the blood.

Understanding Blood Counts

Most chemotherapy affects the Bone Marrow – which is where the body makes most of its blood cells. Blood is made up of three main types of cells:

- Red blood cells
- Platelets
- White blood cells.

Normal Blood Count Ranges

Haemoglobin	115 - 150
Platelets	150 - 400
White Cells	5 - 13
Neutrophils	2.0 - 7.5

Red Blood Cells

The red blood cells carry oxygen around the body. They contain haemoglobin which is the substance that actually transports the oxygen. Chemotherapy can reduce the number of red blood cells in your child's circulation. We aim to keep the haemoglobin (Hb) at around 100. If your child has a low Hb and symptoms of anaemia we may give your child a blood transfusion.

When a child has a low Hb this is called anaemia. Here are some of the signs that may suggest your child has a low Hb or is anaemic and so may need to have a blood transfusion.

- Looking paler than before
- Headaches
- Breathless at times when they normally wouldn't be
- Becoming increasingly tired and lethargic

If your child develops any of these side-effects please contact us for advice.

Platelets

Platelets help the blood to clot. When we injure ourselves, our platelets form a clump around the damaged blood vessel to stop bleeding.

A normal platelet count ranges from 150-400. Chemotherapy can temporarily but significantly reduce the amount of platelets in the blood. If the platelet count is very low a platelet transfusion may be needed. This depends on the severity of any symptoms and how likely it is that there may be a bleed. A transfusion might be needed before some procedures and treatments.

Signs of a low platelet count:

- Bruising
- Nose bleeds
- Bleeding Gums
- A 'petechial' platelet rash (little pink or purple spots)

If your child has any of these symptoms please contact us for advice.

White blood cells

White blood cells are part of the body's defence mechanism; they recognise and fight infections. There are many different types of white cells but we talk most about the neutrophils. Chemotherapy reduces the number of all the white cells, including neutrophils.

Neutrophils - an important white cell for fighting infection

If you have a low neutrophil count you are neutropenic. When the neutrophil count is low the body is at its highest risk of infection, this is when your child is most likely to develop a raised temperature and become unwell. Patients receiving chemotherapy are at high risk of serious and even life threatening infections.

We cannot give transfusions of neutrophils in the same way as we do for low red cells and platelets, and so rely on the bone marrow recovering by itself. It can take several days or weeks for the bone marrow to recover and produce enough white cells to recognise and fight infection.

Common treatment side-effects

Infection

Infection is the most serious of the side effects associated with chemotherapy. There are many different causes of infection, and later in this leaflet we tell you some of the ways you can help to prevent some of them. Often infection can come from bacteria within the child's own body, and cannot be prevented, but should be treated promptly in order to reduce risk.

The first sign of infection is usually a fever. As children can become very unwell with infection it is important to contact us immediately should your child develop a fever above 38°C. It is very likely that your child will need to be seen and assessed in hospital.

Sometimes young children do not develop a fever when they have an infection; there are other signs that you should watch out for:

- 'Shivering' (this can sometimes be called a 'rigor')
- A low temperature below 35.5°C
- Cold hands and feet
- Lethargic and generally 'unwell'

If you are worried that your child is unwell, please ring us for advice.

Do not give Paracetamol (Calpol) until you have spoken to the nursing/medical staff at the hospital. Paracetamol can bring the body temperature down and can mask the signs of infection. This can delay your child getting the antibiotic treatment they need.

Mouth problems

People receiving chemotherapy are at risk of developing problems with their mouth which can include:

- Ulcers
- Gum inflammation and bleeding
- Cold sores (Herpes simplex infection)
- Fungal infections (such as 'Thrush' or Candida)

To reduce the risk of these problems we recommend that your child brushes their teeth twice a day with fluoride toothpaste and a soft toothbrush, which will help reduce the risk for bleeding gums. Some chemotherapy regimens have a very high probability of causing a sore mouth. It is important that you monitor the health of your child's mouth and tell us about any problems.

Hair Loss

Chemotherapy can damage the fast growing cells of the hair. This can affect not only the hair on the head but also body hair and eyelashes. The nursing staff and play team can talk to you about how to prepare your child for this side effect. Wigs hats and bandanas are all available, and can help.

Nausea and vomiting

Some drugs can make your child feel sick (nausea) or actually be sick (vomiting). To reduce the chance of this happening, we use anti-sickness medicines or tablets called anti emetics. If your child still experiences sickness, please inform your doctor or nurse as changing to a different type of anti-sickness medicine or tablet might help.

Diarrhoea & Constipation

It is quite common for children to experience changes in their bowel habits as a consequence of chemotherapy. It is important that we know if this is the case. Sometimes older children may feel embarrassed to talk about these side-effects, but it is important for us to know so that treatment can be given.

If your child has either diarrhoea or constipation they can experience some pain or discomfort. This can be helped by the use of simple methods such as hot water bottles, pain killers and other drugs. Please tell us if your child has any abdominal pain so that we can assess them and try to help.

Children who have diarrhoea can lose quite a large volume of body fluid. This can sometimes lead to dehydration. If your child has a lot of diarrhoea please contact us for advice.

Please always tell us if your child has diarrhoea and /or sickness when you attend the hospital for any visits or admissions. We will assess them and recommend any tests or investigations that need to be carried out. It will help us to stop the spread of any infection which can sometimes cause diarrhoea and sickness.

Sun Protection

When receiving chemotherapy treatment the skin can become more vulnerable to sunlight and burn more easily. We advise that your child wears sun block and is covered up when out in the sunlight for a long time.

Monitoring for treatment side-effects

Your child may need to have a number of tests and investigations to monitor for the side effects of chemotherapy treatment. The tests we do will depend on the type of chemotherapy your child is receiving. We describe here some of the most common tests, but there are others. If you are not sure why your child is having a particular test, please ask us to explain.

Blood tests

As well as checking the full blood count, we do a range of other blood tests. We check the blood electrolytes (salts) regularly. Some drugs, particularly ifosfamide and cisplatin, may cause the kidneys to leak some salts e.g. potassium, phosphate and magnesium, more than usual. If this happens, your child may need to take medicines or tablets to provide extra salts. Some of these salts are also found in food, and the dieticians can advise you what foods can help if your child is low in a particular salt.

DTPA clearance (kidney function test)

Some drugs may damage the kidneys. We check how well the kidneys are working by injecting a very small dose of radioactive dye into the blood and then taking blood samples two hours and four hours after the injection to measure how much of the dye is left in the blood.

Occasionally a child may need an 'extended study' – when further samples are taken. This can take up to eight hours. Unfortunately the dye has to be injected into a different place from where the blood samples are taken. Even if your child has a central line this usually means a separate injection into a vein.

Echocardiogram

Some chemotherapy drugs may cause damage to the heart muscle. An echocardiogram is a scan which will check how well the heart is working. The test is similar to the ultrasound scan done during pregnancy.

Audiogram

Hearing tests need to be done in children receiving certain chemotherapy drugs. These tests require children to cooperate by showing that they can hear various sounds and therefore are difficult to do until children are at least two years old.

Lung function tests

Some chemotherapy drugs can cause some thickening (fibrosis) and stiffening of lung tissue, therefore it is important to check your child's lung function. Measuring lung function requires children to be able to breathe out into a machine and is difficult to do under the age of five.

Eye checks

Children who receive radiotherapy near the eye or total body irradiation need to see the ophthalmologist periodically to check that they are not developing cataracts.

Extravasation of chemotherapy

Extravasation is when fluid or drugs go into the body tissues around a central line or cannula instead of into the vein. Although this is a rare event it can cause damage to the skin.

Signs of this happening are;

- pain at the line or cannula site, or in the chest wall
- swelling of the tissues around the line or cannula, or in the chest wall
- swelling of the veins around the neck

If any of these signs are present, whether you are at home or in hospital, please tell the medical and nursing staff at once.

Chemotherapy and other medicines

Your child may need to take regular medication when they are at home. This will be given and explained to you by the nursing staff or pharmacist. Please bring any medications that your child is taking to any clinic appointments or when they are admitted to the ward.

Storage of Medication

All medication should be kept out of the reach of children. If storage in a fridge is necessary it will be indicated on the bottle.

What if a dose is missed?

It is very important that your child's medication is given as directed. If a dose is missed for any reason, then please contact the ward or clinic for advice. Do not give a double dose when it is next due.

What if my child vomits?

If your child vomits immediately, depending upon what medication it is, you can repeat the dose. If you have any queries please contact the ward. If your child vomits 20 minutes or later, then the medication will have started to be absorbed and should not be repeated.

What if an extra dose is given?

If an extra dose is given by mistake, please contact the ward or clinic for advice.

Some medicines should not be given to children during, before or after receiving chemotherapy. These include medicines containing Ibrufen or similar non-steroidal anti-inflammatory

medicines and certain antibiotics. Paracetamol and Calpol need to be given with caution during chemotherapy treatment. It is important that your child only takes medications that have been authorised by your child's doctors. Please ask a doctor, nurse or pharmacist at the hospital before giving any medicines that have not been prescribed or authorised by us.

How can infection risks be reduced?

The most important way in which the risk of infection can be reduced is by good 'hand hygiene' – as the hands are the most common way that infection is spread. The regular washing and cleaning of the hands by you, your child, and all those who come into contact with your child is the best way to prevent that spread. Soap and water is the best way of washing the hands, and alcohol gel is a good way of quickly disinfecting hands that are already clean.

It is really important to make sure that you and your child always wash your hands after going to the toilet (or for you to wash them after changing a nappy) and before eating or drinking. It is important to make sure that brothers and sisters and other family members keep their hands clean too.

Water

All freshly run tap water from a local authority supply is safe to drink. Ensure you run the tap for a couple of minutes first and that it is from a tap which is used regularly. If you ever receive advice from your local authority that water should be boiled (this sometimes happens if there is a problem with supply) you should do so.

If your water is not from a local authority supply and from a borehole or private water supply this must be boiled and cooled before drinking. This should also be used to wash raw fruit and vegetables and to clean your child's teeth.

When in school or other public places we would advise that your child should not consume water from a communal water fountain.

Avoid still bottled mineral water; carbonated (fizzy) bottled water is safe to drink. Other drinks which are safe include pasteurised cartons or bottles of drinks e.g. fruit juice, Oasis, Drench, Fruit Shoots, Ribena, Fizzy water with a hint of flavouring e.g. lemon, peach etc. All other fizzy drinks.

Some foods are classed as high risk of causing infection and should be avoided during treatment and for up to three months after treatment finishes. Our dietitians will tell you more about this and you can find the information in the 'Eat and Safe Eating for Immunocompromised Cancer Patients' booklet they have produced.

Building materials such as plaster and cement can harbour bacteria and fungus. For a child receiving chemotherapy treatment contact with these can cause serious infections. We therefore advise that children should not be in any form of regular contact with building work both whilst on treatment and for six to twelve months following treatment completion.

If your child has been living in a home with mould or where there has recently been building works it is very important that you tell your consultant so they can decide if they need specific anti-fungal protection.

Frequently asked questions about infection risks

Everyone on the ward uses Alcohol gel; do we need that at home?

No, good hand washing with warm water and soap is adequate. Gel is useful to have if you are out and about and don't have access to a sink to provide a quick decontamination.

Is it safe to go to school?

Yes, a visit to the school will be arranged by your Outreach Nurse Specialist to discuss infections and to support your child getting back into school. If your child is well then we would expect them to go to school regardless of what their neutrophil or white count may be. We advise schools on how to monitor and keep children safe at school and inform them about infection risks, such as chicken pox and measles.

Can we use public transport?

Yes if your child is well. It is important to avoid anybody who is obviously infectious i.e. coughing and sneezing excessively. This is true for all occasions such as visitors to home, going shopping, cinema trips etc.

Do pets carry a risk of infection?

Most pets are O.K., but after handling them make sure your child always washes their hands and avoids handling pet waste. Reptiles can carry Salmonella so we recommend that people wear gloves when handling them and again wash hands well. Please refer to the CCLG booklet 'Handling Animals and Pets'.

Protection from viral infection and immunization

It is important for all children on treatment for cancer to be protected from chicken pox, measles and shingles. Your Outreach Nurse Specialist (Key Worker) will arrange to visit your child's school to discuss with them how to minimize the risk of exposure to these infections so that your child can return to school as soon as possible.

Your child will have a blood test at the start of their treatment to check their levels of immunity to chicken pox. Depending on the result your child may already have a degree of their own protection or they may need treatment to try and protect them from getting chicken pox following a contact.

If your child is in direct contact with chicken pox, measles or shingles or with anyone who develops it within two days of being in contact, you should contact the Ward or the Day Care Unit. Direct contact means that your child is in the same room with anyone who has chicken pox, measles or shingles for a period of fifteen minutes, (or anyone who then goes on to develop the condition within two days of a contact).

If your child has any spots or a rash when you are coming to clinic, or the ward, it is important that you let us know so we can avoid contact with other children on treatment.

Vaccination of Brothers and Sisters against Chicken Pox

If your child does not have any antibodies to chicken pox at diagnosis we recommend that brothers and sisters who have no previous history of chicken pox infection are also vaccinated. This can be arranged through your GP.

Following the chicken pox vaccination of any siblings we recommend that hands are thoroughly washed following visits to the toilet or nappy changes. This is to prevent the possible transmission of chicken pox to the child on treatment. It is possible for the child being vaccinated to develop a rash. If this happens please contact us for advice.

Vaccination of brothers and sisters against measles

It is important that any other children in the family are immunised against measles, your health visitor or GP can arrange this with you as appropriate.

Immunisations during treatment

It is important that children receiving chemotherapy do not have any live vaccines. This includes Measles, Mumps and Rubella (MMR); Oral Typhoid Vaccine; Yellow Fever Vaccines and BCG vaccine (TB vaccine). This applies not just for their time on treatment but also for six months following treatment with standard chemotherapy, or twelve to eighteen months following intensive chemotherapy with either a stem cell or bone marrow transplant.

Vaccination against Influenza ('Flu')

Children receiving chemotherapy should be immunised every autumn with Influenza Vaccine. This applies not only during chemotherapy treatment, but also in the first six to twelve months following treatment completion.

The Immunisation of brothers, sisters, and close family contacts

It is essential that all brothers and sisters of a child with cancer follow their standard immunisation schedule to offer maximum protection to the affected child.

We recommend that all close family contacts (parents, brothers, sisters and any other significant carers) are given the Influenza Vaccine every autumn. This applies not only during your child's treatment but also if your child is either within six months of treatment completion following treatment with standard chemotherapy, or within twelve months of treatment completion following treatment with intensive chemotherapy and stem cell or bone marrow transplant.

The rotavirus vaccine given to infants aged between 6-24 weeks does carry a slight risk of transmission. To minimize transmission we recommend that hands are thoroughly washed following nappy changes.

Re-admission to hospital

Planned admission

You will be given a date for your child's next clinic appointment or hospital admission before going home. If your child is due chemotherapy on their next admission, you will be seen in clinic to check that your child is well and fit for chemotherapy. Before your child's attendance for planned chemotherapy they may need to have further tests and investigations. The ward and clinic nursing team and your Outreach Nurse will help to plan these with you. We may also arrange for your child to have blood tests taken at home or in school by a children's community nurse.

For planned admission for chemotherapy your child will be admitted to the ward or to day care if your child does not need an overnight stay.

Urgent Admission

Please contact us if your child experiences any of the following:

- A temperature of over 38.0°C.
- Vomiting unresponsive to anti-sickness medication.
- Diarrhoea.
- Is not eating or drinking.
- Is not passing urine.
- Develops any rashes, bruising or bleeding.
- Any unexplained or unmanageable pain.
- Comes into contact with measles, chickenpox or shingles as described previously.

- Has a cough, shortness of breath or difficulty breathing.
- If your child's central line (Portacath or Hickman line) site becomes reddened or your child feels unwell after the line has been flushed.
- Any other physical symptoms you are concerned about.

Who should I contact for help and advice

If your child has any of the following problems please contact the day unit during the hours of 9am - 5pm Mon -Fri and at all other times ward L31 or L33

- High temperature (above 38°C)
- Shivery or shakey
- Low temperature (below 35.5°C)
- Unresponsiveness
- Uncontrolled vomiting
- Damaged central line
- Bleeding

If you need help or advice about any of the following problems please contact the Outreach Nurse Specialist team office during office hours Monday - Friday 8.00am to 6.00pm. If no one is available to speak to you please leave a message and the team will call you back **Tel 0113 392 2323**

- Hospital appointments
- Tests or investigations
- Blood tests at home
- Contact with infectious people (ie chicken pox)
- Problems with feeding tubes (nasogastric or PEG tubes)

- Oral medications
- Immunisations
- Hospital transport
- School attendance and education

Going on Holiday

It is important to discuss any plans that you would like to make for a holiday or trip away with your child's Doctor and Outreach Nurse. They can advise you about the most appropriate time in your child's treatment for this. For some children it is not recommended to take a holiday abroad during treatment. You may, however, be able to take a holiday in the UK. Your Outreach Nurse can help you plan for this and put plans in place with local hospitals in case your child becomes unwell whilst you are away on holiday.

Further information

Further information about the department and some of the tests and investigations that your child may have can be found on the Leeds Children's Hospital website:

www.leedsth.nhs.uk/patients-visitors/our-hospitals/leeds-childrens-hospital/

Video's explaining many aspects of care can also be found on Leeds Children's Hospital TV Leeds children's Hospital TV:

<http://www.lchtv.com/>



We hope that the information in this leaflet is helpful and has answered some of the questions or worries that you may have. If there is anything you remain unsure of then please ask any member of the medical or nursing team who will be happy to answer any of your questions.

Useful contact numbers

Ward L31	0113 392 7431
Ward L32	0113 392 7432
Ward L33	0113 392 7433
Children's Haematology and Oncology Outpatient and Day Care Unit	0113 392 7179
Children's Haematology & Oncology Outreach Team (Key Workers)	0113 392 2323
Social Workers	0113 535 1489

Paediatric and Adolescent Oncology and Haematology

What to do if your child has a temperature or they are unwell

If you suspect that your child has a temperature
Take their temperature using a digital thermometer
underneath their armpit.

Is your child's temperature
38°C or above or
below 35.5°C?

YES →

NO

Does your child have any
of the following problems?

Vomiting
Diarrhoea
Shakiness
Excessive sleepiness

YES →

NO

If your child remains well,
has no temperatures of
38°C or above, or any of
the above symptoms they
may remain at home.

**Contact the Ward or
Day Care for advice
if your child has a
temperature or you
are concerned.**

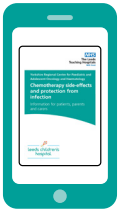
**Ward L31
0113 392 7431**

**Ward L32
0113 392 7432**

**Ward L33
0113 392 7433**

**Day Care
0113 392 7179**

**Please do not give your
child any Calpol or
Paracetamol medications
as this may disguise any
infection that your child
could have.**



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Your views matter



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