Chemotherapy

What is chemotherapy?

Chemotherapy, or chemical therapy, is one form of treatment that involves giving patients anti-cancer drugs. Most of these drugs are known as cytotoxic drugs, which literally means cell (cyto) killing (toxic).

How do the drugs work?

The body is made up of cells and these cells go through cycles of resting, growing and dividing. Different types of cells spend different amounts of time doing these tasks. Cells that grow and divide quickly are more susceptible to chemotherapy. It is during the process of growing and dividing that cytotoxic drugs get into cells and change their make-up so they cannot multiply. As chemotherapy affects cells that divide quickly, it can affect healthy cells too.

Different drugs act at different times of the cycle – some in the growing phase and others in the dividing phase – so for this reason a combination of two or more drugs is often given.

Does chemotherapy have side effects?

Chemotherapy cannot tell the difference between good cells and bad cells, it simply affects all cells that divide rapidly. Damage to normal cells may lead to side effects.

The normal cells most often affected by chemotherapy include those in the –

- bone marrow (where blood is produced) causing low blood counts
- digestive system (mouth, stomach, bowels or intestines, rectum) which may cause nausea, vomiting or mouth/gut ulcers
- hair follicles (hair loss)
- reproductive system (impaired fertility- discuss this with your doctor)
Normal cells repair themselves much more effectively than mutant cells; therefore the side effects caused by damaging healthy cells are almost always temporary.

Different chemotherapy drugs cause different side effects. Also, people respond to chemotherapy differently, some people will have few problems, others more. You will be given specific information pamphlets on all the chemotherapy drugs your child will receive. This information includes how the drug is given, side effects and precautions.

Most of the side effects can be easily managed but it is important for you to let your doctor or nurse know if you notice any side effects.

It is not possible to resolve all side effects of chemotherapy; however, we will do our best to make your child comfortable.

Who decides what type of chemotherapy and how it will be given?

If your child requires chemotherapy, your doctor will provide you with a detailed outline of the planned treatment and a general timeframe of what will happen and when. You may receive a written treatment plan called a protocol.

How is chemotherapy given?

Chemotherapy is given in a number of ways. These include:

- by injection into a vein (intravenous or IV)
- by mouth (oral or O)
- by injection into a muscle (intramuscular or IM)
- by injection under the skin (subcutaneous or SC)
- by injection into the fluid surrounding the spinal cord (intrathecal or IT)

When chemotherapy is given into a vein, it may be given as a quick dose (push) or infused via a pump from a syringe or a bag of fluid over a longer period of time.
When will my child have chemotherapy?

Most chemotherapy is given in cycles where your child will have a course of treatment followed by a rest period. The rest periods allow the body to recover from the side effects of the drugs.

Will chemotherapy hurt?

Oral chemotherapy is just like taking any other medication orally – it does not hurt but some children do not like medicines so the haematology/oncology team will give you some helpful hints for taking medicines.

Injections may be part of your child’s treatment plan and to help reduce the pain we use local anaesthetic cream prior to giving needles. Other measures like ice packs may be helpful for IM injections.

Some children diagnosed with a blood disorder have some form of a central line inserted. (Detailed information explaining these devices will be given to you if required.) These central venous access devices allow chemotherapy and other medications to be given directly into a vein.

If your child becomes very distressed a referral to the psychologist may be helpful. Some children have found hypnotherapy very helpful.

Will my child be admitted to hospital?

Some chemotherapy is given on an outpatient basis at the McGuiness McDermott Children’s Clinic. This may be either a quick push of medication or it may be given over 1-6 hours.

When chemotherapy is given over a longer period of time or requires extra fluid to be given at the same time your child will be
admitted to hospital. When this occurs on the treatment protocol your doctor will explain this to you.

When your child is receiving oral chemotherapy at home you will be given information on how and when to administer this.

**How long will treatment last?**

The length of treatment will depend on the protocol and/or how well your child’s disease responds to the drugs. The doctor will plan the treatment for a certain length of time known to be effective for children with similar types of blood disorders.

**Side effects of Chemotherapy**

Chemotherapy cannot tell the difference between good cells and bad cells, it simply affects all cells that rapidly divide. Damage to normal cells may lead to side effects.

1. **Bone marrow suppression**

Bone marrow suppression is the most common side effect of most chemotherapy drugs. Bone marrow suppression can limit the dose of chemotherapy that can be given and the time between courses. The bone marrow, which is found in the hollow centres of most bones, is the factory where blood is made.
Blood is made up of fluid and cells. There are three main types:

- **Red cells** contain the pigment haemoglobin, which carries oxygen around the body. Lack of red cells and haemoglobin is called **anaemia** and causes paleness and tiredness.

- **Platelets** are involved in blood clotting. When the platelet count is very low, the child may bruise easily and sometimes can have nosebleeds. They may also develop petechiae, which are small red spots under the skin.

- **White cells** are part of the body’s defence system against infection. There are 2 important types of white cell:
  - **Neutrophils** – important in fighting bacterial infections. When the neutrophil count is less than 1.0, the child is said to be neutropenic and is at risk of serious bacterial infections, often with bacteria from within their own body. The lower the white cell count falls, the greater the risk of infection.
  - **Lymphocytes** – important in fighting viral infections and in producing special proteins called antibodies, which help destroy viruses and bacteria.
Infections

Fever

Chemotherapy affects the numbers of white cells and this reduces the child’s resistance to infection. Any fever over 38.5°C or two fevers over 38°C that develops during treatment must be taken seriously and medical advice sought from the specialist or local doctor. You will need to use a thermometer to take your child's temperature. If you do not have a thermometer parents have reported that digital thermometers are much more effective than the expensive tympanic thermometers. Normal temperature is between 36 – 37.5 °C.

If your child has a temperature greater than 38.5 °C with a neutrophil count of less than 0.5 they will require admission to hospital for several days and be treated with intravenous antibiotics. While your child is in hospital your child will be isolated in a single room. If your child has a bacterial infection they may become very ill without prompt medical attention.

There may be times when you are admitted to another ward, if this were to happen then you will be seen by the haematology/oncology team when they do there rounds and they will assist the staff with any questions they may have regarding your child’s care.

Chicken Pox and Measles

Some of the common childhood diseases such as measles, chicken pox or shingles are dangerous to children receiving chemotherapy. These can result in a very serious infection, which can very rarely be fatal. It is very important for parents to contact their doctor as soon as the child comes into contact with somebody suffering from one of these diseases. Contact needs to be direct or close, that is person to person contact. It is important to have the diagnosis of the contact person (the person with the disease) confirmed by a doctor if possible.

Chicken pox and measles are both infectious before the rash appears. For this reason it is very important that parents establish a good communication network amongst their relatives, friends and schoolteachers so that they are notified immediately if someone with whom their child has been in
contact, whether in play or at school, develops chicken pox or measles.

The infectious period for these two illnesses is shown below:

<table>
<thead>
<tr>
<th>Illness</th>
<th>Infectious Period</th>
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<tbody>
<tr>
<td>Chicken Pox</td>
<td>Infectious for 1-2 days prior to rash until all lesions have dried and crusted</td>
</tr>
<tr>
<td>Measles</td>
<td>Infectious from first symptoms of fever, cough, red eyes prior to the rash until the rash fades (usually 4 days from onset of rash).</td>
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Shingles, which is a re-activation of the chicken pox virus in people who have already been infected with the virus in the past, is also potentially infectious and children have been known to catch chicken pox from grandparents with shingles. The infectious period for shingles is the same as for chicken pox and shingles may occur more than once.

Parents and siblings who have already had chicken pox and measles cannot pass the illnesses on from an infected contact to the child receiving chemotherapy.

If your child has come into contact with someone with chicken pox preventative treatment of an antibody is given by injection. This must be given within three days (72 hours) of a contact if it is to be effective, and even then it will only give protection for about 2 to 3 months.

Some parents have found it helpful to send a letter to other parents at childcare or to have information circulated in the school newsletter.

**Mumps and German Measles**

Mumps and German measles (Rubella) are not considered to be dangerous, and no special precautions are required.
Common Conditions

Common conditions such as colds and tonsillitis do not usually present any real problems.

Vaccinations

Vaccines containing live viruses, such as the measles vaccine, are potentially dangerous, because of the risk of producing an overwhelming infection with the modified virus. Live virus vaccines must not be given to children receiving chemotherapy. It is safe to give live virus vaccines to siblings except in the case of oral polio vaccine. As this can be spread through faeces, you should request an inactivated polio vaccine for your other children.

Vaccines, which do not contain live organisms, include influenza, diphtheria and tetanus (CDT). However, the immune response can be diminished while the child is receiving chemotherapy. Sometimes a decision will be made to defer immunisation until after chemotherapy is completed.

At the completion of treatment discuss vaccinations with your doctor.

2. Mouthcare

What is mouthcare?

Mouthcare is regular cleaning of the teeth and gums. During the time children are having chemotherapy or radiotherapy they may need to stop using a soft toothbrush because brushing becomes too harsh on the lining of the mouth, which is when a gentle mouthcare routine should take the place of normal brushing.

Why do we need a gentle mouthcare routine?

Chemotherapy drugs attack and destroy rapidly multiplying cells. The drugs cannot tell the difference between ‘good’ and ‘bad’ cells and may also affect cells that line the gut (gastro-intestinal tract), hair follicles and blood cells. The inside of the mouth is lined with
cells that produce mucous and has a large blood supply. When you have chemotherapy the mouth lining can become weak. When the lining of the mouth is weak it is easier for bacteria to enter the blood stream and cause infection, which can cause a sore mouth or mucositis. Using a gentle mouthcare routine can help to stop or reduce infections.

What is mucositis?
Mucositis is the swelling or inflammation of the mucous membranes (cell lining) of the mouth and gastrointestinal tract. The swelling causes pain and redness that will affect your child’s desire to eat and drink.

What is good mouthcare?
When your child is between treatments and their white blood cell counts are good and they are otherwise well, good mouthcare is:

• Brushing the teeth using a soft-bristled toothbrush and toothpaste at least twice a day after food. This is to stop plaque build-up and prevent gum disease.
• Make sure toothbrushes are clean and replace them every 1-2 months.
• Before a visit to the dentist, let the dentist know your child is having chemotherapy.
• Remember to tell your doctor if a dental problem occurs.
• Keep lips moist by using creams often after brushing. Creams such as lanolin and white soft paraffin will protect against drying and chapping.

When do we need to use a gentle mouthcare routine?
Gentle mouthcare should be started when your child has low white cell counts, and at any time when gums are bleeding or too sore to brush properly. If unsure when to start check with your doctor or nurse.

When is soreness or mucositis likely to happen?
Mouth soreness is likely to happen 7-10 days after chemotherapy has begun. At this time it is expected that the blood cell counts will be lowest, and that is when the lining of the mouth will be weak.
How is a gentle mouthcare routine done?

Mouthcare should be done four times a day, after meals and before bed.

- Rinse the mouth with the mouthwash ordered by your doctor. Dilute 10-15 mls of chlorhexidine mouthwash with 10-15 mls of tap water, swish around the mouth and through the teeth, then spit out. Repeat this action three times.

- For infants or children who can’t rinse their mouths, parents should use jumbo probes soaked in chlorhexidine mouthwash (prepared as above) to wet the mouth, massage the gums and clean the teeth. Use a new probe each time and repeat this three times.

- After the mouthwash an antifungal medication ordered by your doctor. (Eg. Nystatin drops, Miconazole gel or Amphotericin lozenges) is put into the mouth and around the gums. Use the amount shown on the label.

- Nystatin drops can be swished around the mouth, then spat out, or swallowed if that is easier.

- The amount of Miconazole gel is usually just enough to coat around the mouth. A teaspoon, probe or dummy can be used to give the gel.

- Each Amphotericin lozenge must be sucked and allowed to completely dissolve.

It is important to note that food should not be eaten and the mouth not rinsed for 20 minutes after the mouthcare to allow for best effect.

Are there any other mouthwashes that taste better?

There are other types of mouthwash that you may find taste better. If using the recommended mouthwash is a problem ask your doctor for a change. Difflam, Amosan and Ultrafresh are three other mouthwashes you could try.

How do I know if my child has a sore mouth?

If your child can’t tell you their mouth hurts, then look for signs that the mouth is sore:

- Drooling (in younger children)
• Difficulty speaking or opening mouth
• Refusing food and drink or pain when eating
• Difficulty swallowing
• Dry or cracked lips
• Pale, rigid gums
• Redness and / or swelling of the gums
• Bleeding gums
• Mouth ulcers

What should I do if my child has a sore mouth or their gums bleed?
• Stop using a toothbrush and change to a gentle mouthcare routine.
• Drink plenty of fluid, as this rinses the mouth and removes any debris
• Avoid irritating food and drink, such as fruit juices, hot foods, hot drinks and strongly spiced foods.
• Use numbing gel on the mouth and gums before eating to help limit pain. DO NOT use gels that have aspirin in them. The Women's and Children's Hospital recommend Chlorhexidine and Lignocaine gel.
• Give regular paracetamol for pain.
• If your child still can't eat or drink you should contact your doctor and your child may need to come into hospital.
• For advice contact your doctor or nursing staff at McGuiness McDermott Children's Clinic or on Brookman ward.

When can my child return to tooth brushing?
When bleeding and/or soreness have stopped, and the white cell count have improved. The white cell count slowly improves ten to fourteen days after the last chemotherapy treatment. A blood test to check the white cell count is the best way to be sure the count has improved. If you are unsure check with your doctor or nursing staff.

Mouth soreness is an unpleasant and uncomfortable side effect of chemotherapy, but it is only temporary and will not be as severe if it is noticed early and treated straight away.
**Tips to make mouthcare fun**

- Involve brothers and sisters in the game of mouthcare.
- Role-play with Dolly or Teddy.
- Use praise and encouragement; ask for kisses to smell their sweet, fresh breath.
- Play with the swabs, pretending to paint pictures inside the mouth.
- Encourage independence by allowing younger children to hold the swab, put the gel on etc.

3. **Constipation**

Constipation can be caused by some drugs, but this can usually be overcome by the use of laxatives and an adjustment in the child’s diet (refer to the nutrition section).

Avoidance of constipation is very important if your child is receiving a very intensive chemotherapy protocol. Hard faeces can cause a tear (a fissure) in the anal canal (back passage) which may be painful, slow to heal and can be a site of entry of bacteria into the bloodstream (septicaemia). This may result in serious, even life-threatening, infections during periods of neutropenia. (See common terminology).

4. **Sunsmart**

Protection from the sun is important for everyone. It is essential for children having chemotherapy and radiotherapy. Chemotherapy makes the skin more sensitive to the sun and it will burn more easily.

It is important to use factor 30 + sunscreen and long sleeved clothing and hats while outside.

Remember SLIP, SLOP, SLAP and WRAP

5. **Hair Loss (Alopecia)**

**Why does hair loss occur?**

Hair loss occurs when either chemotherapy or radiotherapy interrupts the normal hair growth.
Hair loss can range from very little loss to severe thinning to complete baldness. Hair loss may also include body hair, eyebrows and eyelashes.

Not all chemotherapy drugs will cause hair loss, so it is important to check with your doctor if the drugs your child will receive will cause hair loss. Hair loss can occur more than once depending on the treatment that your child receives.

Hair loss may start within a week or so after starting chemotherapy.

If your child is receiving radiotherapy as a part of treatment, they will experience hair loss also. The hair loss occurs in the path of the radiotherapy beam; hair will fall out in the area of the body being treated. This commonly occurs within weeks of starting radiotherapy.

**Will my hair grow back?**

Yes, hair loss in most cases is only temporary.

After chemotherapy, hair will regrow and this may happen even before treatment has been completed.

You may notice some changes in your child’s hair. It may be a little more curly, thicker or finer than before and may even grow back a slightly different colour.

When radiotherapy is finished, hair usually grows back but it may not be as thick as before. The time it takes to grow back will depend on the dose of radiotherapy and the length of treatment. You should discuss this with the radiation oncologist.

**How to care for hair and scalp during treatment?**

- Use gentle shampoos
- Pat hair dry
- Use a wide toothed comb when hair is wet
- Use a brush with soft bristles
- Use low heat when drying hair
- Avoid plaisting or braiding hair as the pulls and stretches the hair.
- Avoid elastic bands when tying back hair as it breaks the hair.
• If all hair is lost and the scalp becomes flaky gently rub scalp with damp cotton wool, a mild anti-dandruff shampoo might help.

Coping with hair loss.

Hair loss can be a traumatic part of receiving chemotherapy or radiotherapy. Adolescents may be more affected by hair loss than younger children, because adolescents fear being different from their peers.

Talking about hair loss with the haematology/oncology team or with other people who have suffered hair loss may be helpful.

Some people find having their hair cut short before it starts falling out or shaving hair off is best for them. Wearing a bandanna, hair net or a beanie at night can help prevent the loose hairs in the sheets causing itchiness.

What is there to wear?

Hats are great, they come in different styles, and colours and bandannas are also popular.

Wigs are also an option but some find that they are uncomfortable to wear and hot in the summer. If a wig is chosen for a child it is important to remember that they grow and may need to change sizes. To help with wig selection it is suggested that you take a small piece of hair and photo so that the style, colour and texture can be matched.

The cost of a wig may be covered so discuss this with your social worker.

Where can I find help?

You can find further information by asking:

• Your doctor
• Nursing staff
• Social worker

6. Nausea and Vomiting, Loss of Appetite

Nausea and vomiting is a common problem experienced during courses of chemotherapy. Normal tissues can be temporarily damaged by chemotherapy, and some of the cells most affected by the drugs are the ones that line the gut, as well as cells in the
brain, which control nausea and vomiting. This can cause nausea and vomiting, which sometimes can last for a few days after the chemotherapy treatment stops.

The effects of chemotherapy vary with each child and the dose given. A drug that makes one child very ill often has no effect on other children. Because the effects are so variable, each child’s treatment must be worked out for their individual needs.

**What can be done to prevent or treat nausea and vomiting?**

There are some very effective medications available to reduce nausea and vomiting. These are called antiemetics and are best given before chemotherapy. Different drugs work for different people, and more than one drug can be used to give relief. These medications are given either orally (by mouth), or intravenously (into the vein). You will often be given oral medications to use at home if nausea and vomiting continues. In the ‘Nutrition’ section there is dietary information on managing nausea and vomiting.

If vomiting occurs, treat the empty and irritated stomach with a gentle plan to re-establish its normal function:

- If vomiting is persistent, don’t force food down. Sip small amounts of fluid like flat lemonade or glucose drinks. If vomiting is not resolving, call the Haematology/Oncology Unit.
- Carry spare clothes and wipes to places where your child may vomit.
- If vomiting is controlled but the child is still nauseated give diluted milk or fruit juices, weak tea or clear broths to drink. Once fluids are managed, try small amounts of solid food like cereals, yoghurt, or stewed or pureed fruit.
- Avoid any food that triggers symptoms.

**Loss of Appetite**

Most children experience eating problems while on chemotherapy. Children suffering from nausea and vomiting, diarrhoea or constipation, an altered sense of smell or taste, mouth sores, and other uncomfortable side effects, understandably don’t feel hungry. Once more, the damaging of normal tissues lining the gut causes this loss of appetite. As well as the simple loss of appetite, the child may experience a side effect called early filling, where the child feels full after only a few bites of food. This can lead to weight loss and not eating enough of the right kinds of food.
Don’t force your child to eat and discuss this with your doctor. You may also find the ‘Nutrition’ section in the folder helpful.

What can I do to restore appetite and encourage eating? I am worried about my child not getting enough to eat.

There are a number of things that can lead to a loss of appetite:

- A sore mouth can make it hard to eat or drink. Chemotherapy can cause mouth ulcers and reduce the production of saliva. In the ‘Mouthcare section’ there is information on managing a sore mouth.
- Chemotherapy can cause changes in the taste buds, which alters the way your child thinks food tastes. Food that children once loved can now taste bad. The sense of smell is also affected by chemotherapy. Smells can be increased so that smells which others are unaware of can cause a loss of appetite, and cause nausea, during chemotherapy.
- Indigestion can also cause a loss of appetite because of a sore throat or stomach. Medications can be given to treat indigestion or lessen the amount of acid produced by the stomach.

Other tips to lessen indigestion include:

- Chew food well and take time with eating.
- Sit upright while eating and for a while afterwards.
- Try to relax at mealtimes and avoid interruptions.
- Rest after eating.
- Avoid highly seasoned, spicy and fatty foods to reduce indigestion.
- If too much saliva is produced spit it out instead of swallowing it.

Other hints to help stimulate the appetite:

- Eat together as a family whenever possible and encourage meal times to be happy, social occasions.
- Allow access to food at all times.
- Serve food in small, attractive portions.
- Decorate food and drinks.
- Try to plan interesting school snacks that are easy to manage.
- Include favourite treats like takeaways.
• Use the time between treatments to make up for lost eating.

Please remember, if none of the above is working and you are concerned about this aspect of your child’s health, ring McGuiness McDermott Children’s Clinic during the day, and Brookman ward after hours to discuss your concerns.

Nasogastric Tube
Sometimes if your child has lost a lot of weight or is not eating very well, nasogastric feeding is needed. The doctor or dietitian will discuss this with you. A soft plastic tube is passed through the nose to the stomach. A special feed (formula) is then dripped in slowly through the tube often as an overnight feed while they eat normally during the day. This will provide your child with extra nutrients that he/she needs. A nasogastric feed can make it easier and less stressful for both the parents and child in their efforts to eat enough. Don’t be discouraged by the appearance of the tube or the concern of discomfort. Many parents describe tube feeding as a very positive step in maintaining a healthy weight. Medications may also be given via the tube.

If feeds are required for a prolonged period of time a gastrostomy tube can be placed directly into the stomach and feeds given in the same way.
Hypnotherapy

Some children find the injections and the vomiting that may be caused by chemotherapy, become increasingly difficult to cope with. Some children benefit greatly by learning relaxation techniques or using imagery learned through hypnotherapy. These new skills can help the children feel they have some control in the area of treatment.

Children as young as four year old can be helped by these methods. They are best introduced early in the course of treatment. Some parents have used relaxation and meditation to assist them through this stressful time. If you would like more information and feel that your child may benefit from some additional help, please discuss this with a member of the Haematology/Oncology team.