

Caring for a Child with Cancer



All revenue from services treat needy cancer patients.



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Patient information



Shaukat Khanum Memorial Cancer Hospital and Research Centre

Introduction

This leaflet provides basic information and practical advice to help you care for your child when they are having treatment for cancer, to give them the best chance of cure. Treatment may include chemotherapy, radiotherapy or surgery or a combination of the above. Most patients have chemotherapy that will be discussed in greater detail.

The leaflet addresses:

- Common side effects of treatment
- How to prevent side effects
- Frequently asked questions about treatment

What is chemotherapy?

Chemotherapy is treatment with drugs that can be given in the vein or by mouth. The duration of treatment can vary from 2 months to over 3 years depending on the type of cancer. While chemotherapy is very effective in curing cancer it also produces a number of side effects, some of which can be life threatening if not treated promptly and effectively.

Common side effects of chemotherapy

The main side effect of chemotherapy is that it suppresses the body's ability to fight diseases and will put your child at risk of developing infections. This means your child can easily get coughs, colds, diarrhea, skin infections, and other more serious infections. They are also more likely to catch other illnesses that may be more prevalent in your area like malaria, typhoid or hepatitis.

Your doctor will have mentioned side effects from individual medicines but the common side effects are:

1. Repeated infections
2. Painful mouth ulcers and/or abdominal pain
3. Nausea and/or vomiting requiring anti-sickness drugs
4. Difficulty eating leading to poor appetite/diet and weight loss
5. Changes in taste and smell
6. Constipation
7. Diarrhea
8. Fatigue

Certain point to be considered while being treated:

- Keep your child's mouth clean with regular rinsing and brushing

- Avoid arguing, nagging, or punishing a child who is unwilling to eat
- High-fiber foods
- Plenty of fluids
- Take 3 or 4 short naps
- Balanced diet

Side effects of steroid medication?

Steroids (such as Dexamethasone or Prednisolone) are commonly used for the treatment of leukaemia and lymphoma. The side effects include weight gain, tummy pain and behavioural changes. Your child may want considerably more food than usual, less food or completely different food. Most children feel very hungry and demand a certain type of food. Your child may be emotional, moody or irritable. High blood pressure, increased blood sugars and muscle weakness are other known side effects. While the side effects may be worrying they will disappear when the steroids are stopped.

How to Prevent the main side effects and serious infections

Regular blood tests

Your child will have regular blood tests that will show you and the doctors if your child is at risk of developing an infection or if the dose of chemotherapy needs adjustment. The bone marrow is the 'factory' that produces the different types of blood cells, each of which have a different job to do in the body.

Chemotherapy kills cancer cells, but as a side effect it also suppresses the bone marrow that affects the blood count.

There are 3 main types of blood cells that the bone marrow makes:

- Red blood cells (containing haemoglobin) carry oxygen around the body and give your child energy. If the level is low, this is called anemia; your child may be pale and tired, and sometimes may need a blood transfusion.
- White blood cells are the 'soldiers' that fight infections.
- There are different types of white blood cells, but the most important ones are called neutrophils. When the level of neutrophils drops below 1000, this is called neutropenia and your child is at higher risk of serious infection.
- Platelets help the blood to clot properly. If the levels are too low your child may develop bruises, red spots or bleeding such as nose bleeds or bleeding gums. Your child may need a platelet transfusion from time to time.

It is important to have the blood count checked regularly because the dose of

medicine your child is given is adjusted according to these blood count results. Sometimes the medicine needs to be stopped for a period of time. For other cancers the blood counts will inform the doctors whether your child is ready to receive the next treatment.

Management of Infections

If your child has a neutrophil count less than 1000 AND has a temperature it is called febrile neutropenia. This can occur quite frequently without serious consequences but can also be a sign of serious infection that can be fatal in a matter of hours. This is why you **MUST** ring your doctor or go to the doctor immediately if your child has a fever. It is likely that your child will need to be started on intravenous antibiotics (drugs that fight infections). If your child has a temperature, do not give medicine (such as Calpol, paracetamol) to bring down the temperature until your child has been seen by the doctor as this can hide the infection without actually treating it. This means that your child could get seriously ill without anybody realising it. If you have to travel far your doctor may arrange for you to have urgent care closer to where you live to prevent the infection from becoming serious.

- **Seek medical advice immediately if your child has a fever or is unwell whatever the blood count.**
- **No ibuprofen or brufen should be given.**

Maintaining daily hygiene to avoid infections

Maintaining good daily hygiene is essential to help avoid infections.

The following should be adhered to at all times:

- Wash hands thoroughly before giving any medicine or checking any bandages or wounds. Your doctor/nurse will explain the best way to wash your hands properly.
- Wash your hands thoroughly before cooking or preparing any food.



- Where possible a daily bath, clean clothes and good mouth hygiene are very important. Avoid playing in dirty surroundings. Wash your hands before eating and after going to the toilet.



- Freshly cooked, clean simple, food should be provided.



- Clean water supply is also very important.

Avoiding mouth infections

Due to the way chemotherapy works your child's mouth might become sore and painful and/ or develop mouth ulcers that can become infected. You can help reduce the chance of this happening by making sure the teeth are cleaned properly and thoroughly at least twice a day, with a soft tooth brush. If you are provided with anti bacterial spray or mouthwash and sponges please use them as well as ensuring teeth are brushed twice a day.

Avoid contact with contagious diseases

If your child is going to a school or nursery you should tell them they must inform you if your child comes into contact with anyone that has or develops chicken pox or other infectious illnesses.

- Avoid contact with friends and relatives who have colds, open sores, diarrhea

or other infectious illnesses.

- Children undergoing cancer chemotherapy may develop life threatening complications if they have chicken pox or measles. Your doctor will usually enquire at the very beginning of treatment whether or not your child has had chicken pox or has received the chicken pox and measles vaccines. If your child comes in contact with anyone with either of these conditions, you must contact the hospital urgently so that preventive measures can be taken.
- During the malaria season use mosquito netting and insect repellents to avoid getting malaria.
- Both malaria and dengue fever can be prevented by keeping your surroundings clean and draining any stagnant water.
- If the water supply in your area is not safe, give your child only boiled, or filtered water (remember to change filter regularly) to prevent waterborne infections like diarrhea.

Contact with animals

Animals can be a source of infection if they are not looked after properly and kept clean. If your family has a pet you have looked after for a long time, you should keep it. However hands must be washed after contact with pets to avoid infections.

Where possible, contact should be avoided with lizards, farm animals, wild or stray animals and birds. Don't introduce a cat or dog to the house if you don't already have one. If living on a farm and contact or working with animals can't be avoided, clothes must be changed and hands washed thoroughly after contact.

Frequently asked questions about treatment

Why is it important to complete treatment even when my child is in remission and well?

Cancer treatment is given to make sure all cancer cells are killed. If treatment is stopped too soon, the cancer may come back and will then be more difficult to treat. Even if it causes side effects, treatment needs to continue to give your child the maximum chance of cure. However, please discuss this with your doctor because sometimes treatment needs to be modified if side effects are severe.

What should I do if my child misses a dose or vomits his medicine?

For drugs to have the maximum effect, it is essential to give the correct medicine at the correct dose and at the correct time. However, if your child forgets to take his medicine, inform your doctor. Do not double the next dose. If your child vomits the medicine do not give another dose as the amount absorbed prior to vomiting cannot be calculated.

What foods should I give my child?

- All kinds of fresh home-cooked food is recommended.
- Do not reheat old food.
- Only give your child fruit that can be peeled i.e. bananas, melons & oranges.
- Fish, chicken and eggs are fine if your child likes them. These should be cooked thoroughly and served fresh.
- Avoid take away food or food from vendors. This includes ice creams and sweets. Your child may have crisps or packaged biscuits, chocolates or candies.
- Boil drinking water for 20 minutes and cool in the same container. Bottled drinking water is fine. A water filter should only be used if it is changed frequently as recommended.

Remember unclean water can cause serious infections

Can my child go to school?

After the intensive phases of therapy your child should go to school if your doctor thinks your child is well enough.

Who can my child play with?

Your child can play with brothers and sisters. Your child can also play with friends if the friends don't have an infection or cold. Cancer is not infectious. Brothers and sisters or friends will not get cancer from eating/playing with the affected child.

Cancer is not contagious and cannot spread by contact

Important contact numbers:

If the patient has to be taken out of the city due to any reason or compulsion, contact the doctor and be sure that it will not be unsafe to take the patient. In other city, if your child gets unwell (e.g. fever, vomiting, loose stools, abnormal body movements, difficulty breathing, feelings tired) take him/her immediately to nearest hospital and call Shaukat Khanum Hospital on +92-42-35909500 and emergency extension 5136, 5137 or 4032.

After providing first aid to the child, leave for Lahore on local doctor's advice.
Important contact number:

Outpatient reception: 3432, 3433, 3436

Chemo bay: 5012, 5013, 5014, 5017

OPD clinic: 8007

It is better for the patient's health to stay at Lahore during cancer treatment to reach the hospital in case of any emergency.

This booklet provides only basic information. Your doctor is the person who knows your child's health better, so follow his/her advice.

Reference:

This booklet is written by CCLG Paediatric oncology Group (PODC). This group consist of oncologists and nurses for the treatment of child cancer patients.
<http://www.cclg.org.uk/treatment-research/caring-for-a-child-with-cancer-in-developing-countries>

A decorative graphic consisting of a grey five-pointed star at the top center, two overlapping light orange circles below it, and two grey curved bands at the bottom. The text is centered within the white space between the two orange circles.

MISSION STATEMENT

To act as a model institution to alleviate the suffering of patients with cancer through the application of modern methods of curative and palliative therapy irrespective of their ability to pay, the education of health care professionals and the public and perform research into the causes and treatment of cancer.