Coping with CHEMOTHERAPY

CANCER PATIENT’S AID ASSOCIATION
Total Management of Cancer
www.cancer.org.in
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Cancer Patients Aid Association (CPAA), a registered charitable non-governmental organisation (NGO), was started in 1969 mainly to provide financial assistance to needy cancer patients. Over the last forty three years the organisation has expanded its mission to address the root cause of the exponential increase in cancer cases in India, namely that of lack of knowledge and information. CPAA complements the work being done by medical practitioners and hospitals, concentrating on education and awareness, early detection, insurance, support to treatment, guidance and counseling and rehabilitation. Our mission is ‘Total Management of Cancer’. CPAA has grown from a tiny Mumbai based organisation surviving on small donations to one with branches in Delhi and Pune. CPAA draws its entire annual budget from corporate and individual donations.

CPAA’s main aim is to:

• Spread awareness on the dangers inherent in accepted social practices such as chewing of tobacco, early marriage and multiple pregnancies, which are responsible for approximately 70% of cancers in India.

• Initiate steps for the early detection of cancer since treatment at this stage leads to a cure in a majority of cases.

• Provide complete assistance to cancer patients beyond that given by the medical profession, taking a holistic approach.

Our activities which encompass every area related to cancer are: Awareness, Advocacy, Early detection, Insurance, Patient Care, Rehabilitation Centre, Tobacco Cessation Centre and a Volunteers Training Programme.

1. CHEMOTHERAPY TREATMENT

Cancer is the uncontrolled growth of cells coupled with malignant behavior. Chemotherapy is the treatment of cancer that uses anti-cancer (cytotoxic) drugs or chemotherapeutic agents to destroy cancer cells. It works by stopping or slowing the growth of cancer cells, which grow and divide quickly. More than 100 chemotherapy drugs could be used in various combinations by the treating medical Oncologist (Onco-physician) including the dosage, frequency and length of treatment what is best for the patient. Chemotherapy procedure does not use ‘chemicals’.

As chemotherapy affects cell division, tumors with high growth fractions (such as Acute Leukemia and the aggressive lymphomas, including Hodgkin’s Lymphoma) are more sensitive to chemotherapy, as a larger proportion of the targeted cells are undergoing cell division at any time. Malignancies with slower growth rates, such as indolent lymphomas, tend to respond to chemotherapy much more modestly.

Depending on the type of cancer and how advanced it is, chemotherapy can do the following:

• **Cure (Early stages):** When chemotherapy destroys cancer cells to the point that the doctor can no longer detect them in the patient’s body and they will not grow back.

• **Control (Advance stages):** When chemotherapy keeps cancer from spreading, slows its growth, or destroys cancer cells that have spread to other parts of the body.

• **Ease symptoms (Palliative care):** When chemotherapy shrinks tumors that are causing pain or creates pressure on other organs.

Sometimes chemotherapy is used as the only cancer treatment (ex.: Leukemia...
or Lymphoma), but often a combined treatment is used in conjunction with other cancer treatments, such as radiation therapy, surgery or biological therapy. Combination chemotherapy is a similar practice that involves treating a patient with a number of different drugs simultaneously. The drugs differ in their mechanism and side effects. The biggest advantage is minimizing the chances of resistance developing to any one agent.

Goals of chemotherapy may vary for each patient’s condition as follows:

i. **Neo-adjuvant Chemotherapy (preoperative treatment):** It is designed to shrink the primary tumor, thereby rendering local therapy (surgery or radiotherapy) less destructive or more effective. This helps preserving an organ (ex.: Breast conservation)

ii. **Adjuvant Chemotherapy (postoperative treatment):** It is used when there is microscopic/minimal cancer present, but there is risk of recurrence (after surgery or radiation therapy). This can help reduce chances of relapse. It is also useful in killing any cancerous cells that have spread to other parts of the body (metastatic cancer) This is often effective as the newly growing tumours are fast-dividing, and therefore very susceptible to chemotherapy.

iii. **Palliative Chemotherapy :** It is given without curative intent, but simply to decrease tumor load and relieve symptoms, increase life expectancy. For these regimens, a better toxicity profile is generally expected.

2. **HOW IS CHEMOTHERAPY GIVEN ?**

Most anticancer drugs are given by one of the following methods as described below:

i. **Oral** - (giving the drugs by mouth) Medicine is given by mouth and travels into the bloodstream through the lining of stomach or upper intestine. Tablets may be given to take at home with other specific instructions such as whether or not to take them with food. If for any reason the tablet is not taken on time, the doctor should be contacted immediately for guidance.

ii. **Intramuscular** - Drugs are given into a muscle with an injection

iii. **Intravenous (IV)** - This is the most commonly used method of administering chemotherapy drugs. Drugs are injected directly into the vein and enters the bloodstream very rapidly. Chemotherapy drugs which can irritate healthy tissue may be administered in IV fluids which help to dilute the chemicals in the drug. The modes used are, catheters, ports or pumps.

   a. **Catheters** - A catheter is a soft, thin tube. A surgeon places one end of the catheter in a large vein, often in the chest area, while the other end of the catheter stays outside the body. Most catheters stay in place until all the chemotherapy treatments are done. Catheters can also be used for drugs other than chemotherapy and to draw blood. Be sure to watch for signs of infection around your catheter.

   b. **Ports** - A port is a small, round disc made of plastic or metal that is placed under the skin. A catheter connects the port to a large vein, most often in the patient's chest. The nurse can insert a needle into the port to give you chemotherapy or draw blood. This needle can be left in place for chemotherapy treatments that are given for more than 1 day. Be sure to watch for signs of infection around the port.
c. **Pumps** - Pumps are often attached to catheters or ports. They control how much and how fast chemotherapy goes into a catheter or port. Pumps can be internal or external. External pumps remain outside the body. Most people can carry these pumps with them. Internal pumps are placed under the skin during surgery.

iv. **Intrathecal** - The drug is injected into the spinal canal.

v. **Intra –Arterial** - The drug is injected directly into an artery to treat a single area (such as the liver, an arm or leg). This method limits the effects of the drug on other parts of the body.

vi. **Intra cavitary** - Drugs are given through a catheter into the abdominal cavity or chest cavity.

3. **DOSAGE**

Dosage of chemotherapy can be difficult: If the dose is too low, it will be ineffective against the tumor, whereas, at excessive doses, the toxicity (side-effects) will be intolerable to the patient. This has led to the formation of detailed 'dosing schemes' (protocols) based on various scientific studies and published data, which give guidance on the correct dose and adjustment in case of toxicity.

In most cases, the dose is calculated based on the patient's body surface area, a measure that correlates with blood volume by the Onco-physician. If the side effects become severe, the doctor may decide to delay the chemotherapy, which will reduce the dose intensity. Reducing the dose intensity should only be done when the doctor has considered the risks and benefits in view of Chemotherapy, and is given according to a protocol (plan). The dose and frequency depend on the kind of cancer, the drugs being used and how patient’s body responds to them. It may be given daily, weekly or after 3 weeks, sometimes treatment is given in an on and off cycle that includes rest periods so that your body has a chance to build healthy new cells and regain strength. The number of cycles and the length of treatment vary for each and every individual depending on their conditions. Cancer is complex. The same type of cancer can affect patients differently. A specific drug regimen is therefore tailored to the needs of the patient taking it. This is called 'personalized treatment'.

4. **SCHEDULE OF CHEMOTHERAPY**

The chemotherapy cycles are given on a schedule based on the patient’s treatment goals, how the drugs in patient’s regimen work and how the body reacts to the treatment. Different drugs work at different times in the cell cycle (division and growth process of cancer cells). The goal of the schedule is to give the chemotherapy drugs as often as possible while minimizing side effects that could interrupt that schedule.

Staying with the treatment plan the doctor prescribes, is important. Studies have shown that patients with certain cancers who were able to take most of their planned dose of chemotherapy had better treatment results. But the doctor may reduce the dose or delay it because of specific side effects from the chemotherapy. It is important to communicate with the doctor and care team before each cycle to find out ways to help manage any side effects that can result in dose reduction.
Drug regimen is tailored to the needs of the patient by the Onco-physician on the basis of the following:

- The type of cancer
- The stage of the cancer (its size and how far it has spread)
- Patient’s age and overall health (other medical problems, e.g., Cardiac illness)
- Treatment goals

**Treatment Interruptions**

If one or more side effects from the chemotherapy become severe, the doctor may decide to reduce the dose or change the schedule of future treatment cycles. Typical side-effects that may cause treatment interruptions are low blood cell counts causing neutropenia, anemia and thrombocytopenia. In some cases, nausea and vomiting may also become severe enough to delay the scheduled treatment.

**Place of treatment**

The location depends on which chemotherapy drugs are being administered. Oral chemotherapy can be taken at home. Other types are given in daycare clinics or in hospital wards. The initial treatment may require a short stay in the hospital so that the doctor can closely watch the medicine’s effect and adjust the dose if necessary.

5. **ANSWERS TO SOME TYPICAL QUESTIONS**

i. **Does Chemotherapy hurt?**

   Normally a short discomfort is felt with the injection. Intra vascular (IV) medicine should not hurt after the initial needle prick to insert the catheter.

   The doctor or the chemotherapy nurse should be informed immediately in case of pain, burning, coolness or other unusual sensations.

ii. **Can I take other medicines during chemotherapy?**

   Some medicines may interfere with the effects of your chemotherapy. So before starting treatment a list of the current medicines taken, their strength, frequency and purpose should be given to the doctor. Even laxatives, cold pills, aspirin and vitamins should be included.

iii. **Can I work during Chemotherapy?**

   Many people can work during their chemotherapy depending on their nature of job, their work schedule and how they feel. If the job allows, explore the possibility of working part time or working from home on days you do not feel well. Many employers are required by law to facilitate a change in the work schedule to meet the needs of an employee undergoing cancer treatment.

   It is best to be open and talk to the employer about it. Speak to a hospital social worker for more information.

iv. **Can I drink alcoholic beverage?**

   Small amount of alcohol can help you relax, but it may interfere with the effectiveness of some drugs or worsen their side effects. Make sure you consult your doctor about it.

v. **How will I know if the Chemotherapy is working?**

   Your cancer care team will measure how well your treatments are working through frequent physical examinations, blood tests and x-rays or scans. Ask your doctor about the test results and what they show about your progress. You may not have side effects, but that does not indicate that the drugs are not working. Side effects have no correlation with effectiveness of the drugs.
vi. **What are clinical trials and are they an option for me?**

Cancer clinical trials (also called cancer treatment studies or research studies) test new treatments for people with cancer. These can be studies of new types of chemotherapy, other types of treatment, or new ways to combine treatments. The goal of all these clinical trials is to find better ways to help people with cancer. Your doctor or nurse may suggest you take part in a clinical trial. You can also suggest the idea. Before you agree to be in a clinical trial, learn about:

a. **Benefits**: All clinical trials offer quality cancer care. Ask how this clinical trial could help you or others. For instance, you may be one of the first people to get a new treatment or drug.

b. **Risks**: New treatments are not always better or even as good as standard treatments. And even if this new treatment is good, it may not work well for you.

Participating in a clinical trial is absolutely voluntary.

6. **CAUSES OF SIDE EFFECTS**

Chemotherapy drugs are meant to kill fast growing cells but because these drugs travel throughout the entire body, they can affect normal, healthy cells. Damage of healthy tissue is the cause of side effects. Side effects are not always as bad as one might expect although many people especially worry about this aspect of their cancer treatment. All such side effects get better or go away after chemotherapy is over. Side effects vary from patient to patient due to different drugs and protocols used. Patient’s own attitude is also important.

'A positive frame of mind ensures better recovery'

7. **COMMON SIDE EFFECTS AND THEIR COPING MECHANISMS**

The most prevalent side effects of chemotherapy include:

Nausea and vomiting, hair loss, fatigue, increased chance of bruising and bleeding, diarrhea / constipation, anemia and infection, low platelet count (Thrombocytopenia) and problems with thinking and memory (rare).

Chemotherapy may affect also specific parts of the body giving rise to intestinal problems, appetite and weight loss, sore mouth, gum or throat, nerve and muscle problems, dry skin, kidney and bladder irritation, sexual problems and infertility effects on reproductive organs. It should be remembered that everybody may not experience all side effects. The occurrence and severity of side effects varies greatly from person to person. The patient should inform the doctor about the problem, he may prescribe medicines which would help. Most side effects gradually disappear after treatment ends as the healthy cells recover quickly.

The time of recovery and gaining back energy varies and depends on factors including the overall health and the specific drugs that have been given. Be sure to talk to your onco-physician about drug-specific side effects.

i. **Managing nausea and vomiting:**

They are the most common side effects. Fortunately, both these symptoms can be significantly reduced by a change diet and with the help of medicines that relieve nausea and vomiting. There are excellent drugs available now to prevent nausea and vomiting.

The following measures can help:

a. Avoid heavy meals. Resort to smaller frequent meals if necessary.

b. Preferably drink liquids approximately an hour before or after meals.

c. Eat and drink slowly.
d. Avoid fried and fatty foods.

e. Chew your food well.

f. Drink cool, clear unsweetened beverages like fruit juice.

g. If you are fond of aerated drinks, let the fizz escape before drinking.

h. Suck on ice cubes or mint candies.

i. Keep away from smells which you do not like.

j. Regularly practice deep breathing.

k. Wear loose fitting clothes.

l. Try to distract yourself with activities which you like.

II. Dealing with hair loss: Hair loss (alopecia) is fairly common. Not all chemotherapy drugs will make you lose your hair. Some people experience mild thinning that is noticeable only to them. Even if you do lose your hair, it will always grow back after the treatment is over, however it might change its texture and fullness. The following techniques may help reduce hair loss. Use mild shampoos and soft brushes, avoid using a hair drier, do not use hot rollers to set your hair, do not dye hair, and have a short hair cut to give a fuller look. Using a wig is a good idea in case there is total hair loss and until the fresh growth appears.

III. Dealing with fatigue: Fatigue is one of the most common side effects of chemotherapy. It can range from mild lethargy to feeling totally wiped out. It tends to be worst at the beginning and at the end of the treatment cycle. Like most other side effects, it will disappear once the chemotherapy is over. The best way to cope with this is to have adequate rest and proper sleep at night and naps during the day. If necessary, reduce your activities, do not over exert and do not be hesitant to seek assistance for any activities you might not be able to accomplish. Eat a well-balanced diet and drink plenty of water, talk to your doctor or nurse for a program of regular exercise.

IV. Causes of infection and how to deal with it: Most anti cancer drugs affect the bone marrow, decreasing its ability to produce blood cells. The white blood cells produced in the bone marrow help to protect the body by fighting bacteria that cause infection. If the number of white cells in your blood reduces there is a higher risk of getting an infection. Infection can begin in any part of your body. If the white blood cell count drops too much, the doctor may postpone treatment, give a lower dose of chemotherapy, or prescribe treatment to increase the production of white blood cells.

Techniques to prevent infections are as follows:

a. Keep your hands clean, washing them as often as required.

b. Stay away from people who have contagious diseases such as cold, flu, measles or chickenpox.

c. Avoid crowds.

d. Clean your rectal area gently but thoroughly after each bowel movement. Take advice of the doctor if the area becomes irritated or if you have piles.

e. Avoid cuts or wounds of even the smallest kind, like cutting your nails, cuticles, handling sharp instruments, shaving, brushing your teeth or to clean it and apply an anti-septic medicine.
f. Do not squeeze or scratch pimples.
g. Protect your scalp from sunlight with a scarf or cap or hat if you happen to lose a lot of hair.
h. Do not get any immunization shots without checking first with your doctor.
i. The symptoms of infection include fever of 100.5 degrees or more, chills, sweating, loose bowels, a burning feeling when you urinate, a severe cough or sore throat, unusual vaginal discharge or itching, redness, swelling or tenderness especially around a wound or abdominal pain. Report any signs of infection to your doctor immediately.
j. Balanced nutrition and a proper diet help you to succeed in re-establishing the metabolic balance you need to fight cancer.

V. Dealing with diarrhea: If you have diarrhea that continues for more than 24 hours or if you have pain and cramping along with it, call your doctor. Do not take any anti-diarrhea medicine without asking your doctor. To control diarrhea eat smaller amounts of food, avoid tea, coffee, alcohol and sweets, high fiber foods like beans, nuts and fresh and dried food, stay away from fried, greasy or spicy food, avoid milk products and drink plenty of fluids to replenish the water loss along with potassium-rich foods like bananas and oranges.

VI. Dealing with constipation: Some people become constipated from chemotherapy. Check with your doctor if you have not had a bowel movement in two or more days. To deal with constipation drink plenty of fluids to help loosen your bowels, eat high fiber foods like bran, whole bread, cereals, cooked vegetables, fresh and dried fruits and nuts. Also try to get some exercise.

VII. Low Platelet Count (Thrombocytopenia - rare): Chemotherapy destroys cells that grow rapidly, including those in the bone marrow that produce platelets. A low platelet count, also known as thrombocytopenia, is an uncommon side effect except for patients with blood cancer (Leukemia). In case of a cut or bruise, platelets form plugs in the blood vessels to stop the bleeding. A low platelet count (less than 20000/ml) can lead to serious blood loss, which can damage internal organs. Thrombocytopenia can also delay your chemotherapy while your doctor works to improve your platelet levels. This problem may be severe if a patient is taking Anti platelet agents (for cardiac disease). During chemotherapy you should try to avoid getting cut, bruised, or injured in any way that may cause bleeding:
a. Shave with an electric razor instead of a blade
b. Use a soft-bristle toothbrush
c. Wear proper fitting shoes all the time—indoors and out—to avoid cuts on your feet
d. Blow your nose carefully

VIII. Problems with thinking and memory-‘chemobrain’- Some chemotherapy treatments (especially the ones used for breast cancer treatment) have been linked to problems with memory, learning and thinking. This particular side effect is often referred to as 'chemobrain'. Though most patients will regain their normal abilities to think and remember after the chemotherapy cycle ends, these side effects may continue in some patients.
Managing Chemobrain - There are things you can do to try to reduce the impact of chemobrain on your everyday life:

a. Minimize distractions when completing tasks.
b. Use a daily organizer to help remember appointments.
c. Record reminders on answering machine.
d. Make lists of tasks to do and cross them off on completion.
e. Get plenty of sleep.
f. Let your friends and family know if you are having trouble thinking and remembering.
g. They can help by reminding you of important events and appointments.

Your problems with memory and concentration may improve once you complete your chemotherapy treatment. However, some patients may continue experiencing a chemobrain for years after treatment has ended. Knowing which patients will have ongoing difficulties is hard to predict, since the way chemotherapy causes these problems is not well understood.

IX. Numbness and Tingling - Peripheral Neuropathy - Areas of the body most commonly affected by peripheral neuropathy are the hands, feet, fingers and toes. Symptoms usually start at the fingers and toes and may gradually move upward to the hands, feet, arms and legs. The feeling of tingling or numbness in hands or feet is called peripheral neuropathy. Peripheral neuropathy can be a side effect of some chemotherapy medicines. It is caused by damage to the nerves that send signals between the arms and legs and the central nervous system. Other symptoms in addition to numbness and tingling may include: intermittent stabbing pain, burning sensation, muscle weakness, numbness in the affected areas, inability to feel pressure or sense hot or cold temperatures and trouble keeping balance.

Treating Peripheral Neuropathy - The main goal of treatment for chemotherapy-induced peripheral neuropathy is to reduce symptoms. Treatments may include medications and physical therapy. Recovery from peripheral neuropathy can be slow, and symptoms may persist. Some approaches that may help include:

a. **Strict** control of blood sugars for diabetic patients
b. **Acupuncture** relieves pain in some patients. Ask your doctor for more details and the name of a licensed acupuncturist.
c. **Massage** can increase blood flow and may provide pain relief.
d. **Exercise** may help with neuropathy pain.
e. **Medicines** may help relieve pain and discomfort and reverse neuropathy
f. **Transcutaneous nerve stimulation (TENS)** is a therapy using a special machine that sends an electrical current through electrodes attached to your skin. (after asking your Oncologist)

X. Sexual function and fertility: Chemotherapy can but does not always affect sexual organs and their functioning. In men, the main problem noted is a reduction in the number of sperms. This can affect fertility, but not the ability to have a satisfactory sexual intercourse.
In women, chemotherapy can have more wide ranging effects as follows:

- Damage to ovaries resulting in hormonal deficiencies; menstrual period may become irregular or stop completely during chemotherapy, menopausal symptoms may arise resulting in infertility. In younger patients these are temporary problems, but women over 40 years of age may get permanent menopause.

- Pregnancy during chemotherapy to either partner is not advisable. These drugs can influence the sperms or the ova. Effective birth control measures should be taken. You may discuss semen preservation or oocyte preservation with your Oncologist for a future pregnancy.

**XI. Emotional effects:** Chemotherapy can bring major changes to your life. It can affect your general health, threaten your well being, disrupt your daily routines and put a strain on your relationships.

It is normal and understandable for the patients and family to feel sad, anxious, angry or depressed. There are ways to cope with these emotional side effects, like talking to a counselor, an understanding friend, relative or another patient. Pursuing a hobby to divert, will help. Thinking positive is also very important. The best way to cope with emotions and stress resulting from cancer treatment is to ensure that the mind and body are fighting together.

8. **TIPS FOR MEETING WITH YOUR DOCTOR**

- **Make a list of your questions before each appointment.** Some people keep a 'running list' and write down new questions as they think of them. Make sure to have space on this list to write down the answers from your doctor or nurse.

- **Bring a family member or trusted friend to your medical visits.** This person can help you understand what the doctor or nurse says and talks with you about it after the visit is over.

- **Ask all your questions.** There is no such thing as a stupid question. If you do not understand an answer, keep asking until you do.

- **Take notes.** You can write them down or use a tape recorder. Later, you can review your notes and remember what was said.

- **Ask for printed information about your type of cancer and chemotherapy.**

- **Let your doctor or nurse know how much information you want to know,** when you want to learn it, and when you have learned enough. Some people want to learn everything they can about cancer and its treatment. Others only want a little information. The choice is yours. But there will be a limitation to your understanding as you are not a doctor. Have full faith in your doctor and the team taking care of you.

- **Find out how to contact your doctor or nurse in an emergency.** This includes who to call and where to go.

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