# A Patient Guide to Chemotherapy and Biotherapy

New Mexico Hematology and Oncology Specialists

# **Contact Information and Hours**

To contact the New Mexico Hematology and Oncology Specialists staff or office, please call **575.736.8256**.

# **Business Hours:**

Monday to Thursday 8am to 12pm • 1pm to 5pm (Closed for lunch 12 pm to 1 pm)

Friday 8am to 12pm

Saturday & Sunday Closed

# **After Hours:**

To contact a New Mexico Hematology and Oncology Specialists nurse or physician after business hours, on weekends or holidays, please call 575.736.8256.

You will reach the answering service. Let them know your name and the name of your physician, and they will put your call through to the nurse or physician.

**NOTE:** The after hours number is for urgent and emergent situations and should not be called for scheduling or billing questions.

# **Your Medicine Information**

# What medicines will I be taking?

| What medicines will i be taking.                        |  |
|---|--|
| Your chemotherapy protocol is called:                   |  |
|   |  |
| Your chemotherapy will be given every:                  |  |
|   |  |
| Chemotherapy medication(s):                             |  |
| 2   |  |
| 3   |  |
| 5   |  |
| 5   |  |
| Your nausea medication(s) and how to use them:          |  |
| 1   |  |
| 3   |  |
| 4   |  |
| 5   |  |
| Other medication (a) your dectar base and medicate upon |  |
| Other medication(s) your doctor has ordered for you:    |  |
| 2   |  |
| 3   |  |

# Introduction

The team at **New Mexico Hematology and Oncology Specialists**, a division of **Artesia Healthcare Professionals**, has prepared this guide in order to help you understand more about cancer and its treatment. It will discuss the main cancer treatments, including chemotherapy, targeted therapy and immunotherapy, as well as surgery and radiation therapy.

As your Medical Oncology Center of choice, New Mexico Hematology and Oncology Specialists provide treatment using therapies that have been approved for different cancers. Chemotherapy may be used as an umbrella term to describe all cancer therapies, including targeted and immune system stimulating treatments that are now used more widely and to accurately target cancer cells.

We will address the different side effects experienced by different people, and discuss how best to cope with them. Reactions will vary depending on the type of drug used, and from one chemotherapy treatment cycle to the next, but most are temporary and can be controlled or reduced.

We hope the information in this booklet will answer some of your questions, and can supplement the face-to-face patient education you and your caregivers will receive over the course of your treatment.

There's no need to read it from cover to cover—you can just reference whatever parts are useful to you, and can clarify whatever questions might come up.

We've developed this content with help from a range of reliable sources, other cancer guides, medical reference texts, health professionals at New Mexico Hematology and Oncology Specialists and even former chemotherapy patients. If any of the terms are unfamiliar, feel free to use your favorite search engine to look up definitions. But be careful: many search results are not filtered, and could be unreliable. Remember, you can always talk with your doctor or nurse about what to expect during cancer therapy.

The use of product or brand names that appear in this book are only intended as examples. New Mexico Hematology and Oncology Specialists do not endorse any specific product or brand. If products or brands are not mentioned, it does not mean or imply that they are not satisfactory. We want to thank the National Cancer Institute and American Cancer Society for providing the template to present this information to patients like you.

Most importantly: however scared or apprehensive you may be about your chemotherapy treatment, we hope that the content of this booklet can help you feel empowered and informed in your care.

Yours Sincerely,



Ajaz Bulbul, MBBS, MD Medical Director New Mexico Hematology and Oncology Specialists Artesia General Hospital

# **Your Cancer Care Team**

# New Mexico Hematology and Oncology Specialists and Artesia General Hospital

| Health Professional                                     | Role  |
|---|---|
| Medical Oncologist/Hematologist                         | Cancer specialist to prescribe and coordinate medical             |
|   | treatments for solid and blood cancers with chemotherapy,         |
|   | immunotherapy and targeted treatments                             |
| Surgical Oncologist                                     | A surgeon specializing in surgically removing cancers             |
| Radiation Oncologist                                    | A specialist trained in killing tumor cells by using radiation    |
|   | therapy—typically, in coordination with the medical               |
|   | oncologist  |
| Advanced Nurse Practitioner (Nurse Practitioner)        | An advanced practice registered nurse trained in managing         |
|   | medical complications of treatments and who coordinates           |
|   | with a medical oncologist to provide a holistic approach to       |
|   | care  |
| Oncology Nurse  | Our highly trained registered nurses specializing in all          |
|   | aspects of preparing and infusing chemotherapy, as well as        |
|   | coordinating care   |
| Pharmacist  | Trained professional in preparing chemotherapy in a highly        |
|   | contained and sterile environment; helps maintain safety by       |
|   | providing advice on drugs and dispensing them                     |
| Dietitian   | Professional who helps develop a nutritional plan for you         |
|   | during treatment  |
| Behavioral Health Team                                  | Psychiatrist and other members of the team to help with           |
|   | psychological distress  |
| Financial Team  | Billing specialists who help make sure your treatments get        |
|   | approved by insurance providers and help you cover the            |
|   | cost of drugs   |
| Front Staff   | Staff to help check you in and make sure all your paperwork       |
|   | is in order; they will ask you to fill out questionnaires helpful |
|   | for genetic screening or patient visits                           |
| Scheduler   | Specialist in scheduling and coordinating procedures and          |
|   | infusion treatments; they also work with the other members        |
|   | of the team   |
| Pain Management/Palliative Care                         | Support services for pain management                              |
| Social Services, Physical Therapy, Occupational Therapy | Support services to help you resume your normal activity          |
| Clinic Manager  | Manager to help address your concerns and maintain                |
|   | coordination between your team and outside physicians             |
| Cancer Care Team  | All your providers at Artesia General Hospital, both within       |
|   | New Mexico Hematology and Oncology Specialists and                |
|   | outside, who provide radiology, diagnostic and surgical           |
|   | services  |
| Interventional Radiologist                              | Radiologist who specializes in doing small needle biopsies of     |
|   | tumors  |
| Radiologist   | Specialist who reads and interprets images from CT, PET and       |
|   | MRI scans, in addition to other tests                             |

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## Cancer Treatment Guide for Patients & Providers | New Mexico Hematology and Oncology Specialists (NMHOS)

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# What is Cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This abnormal cell usually develops due to a mutation (abnormal genetic change) that occurs within it. This rogue cell may coerce its environment to produce blood vessels and lymphatics to help it grow and eventually spread. These cells actively develop systems to hide from our body's immune system which under normal conditions recognizes and clears these bad cells. All of this causes the tumor cell in that organ to grow into a 'tumor,' 'mass' or 'lump' which can look like a ball or a sheet of abnormal cells. A tumor can be benign or malignant: a benign tumor has not yet developed the capacity to spread (or metastasize) outside the area where it grows. A malignant tumor's abnormal cells have developed genetic mutations that allow it to spread far and wide throughout the body. This is what leads to stage IV, or metastatic cancer.

Benign tumor – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumor – Cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid) make up this kind of tumor.

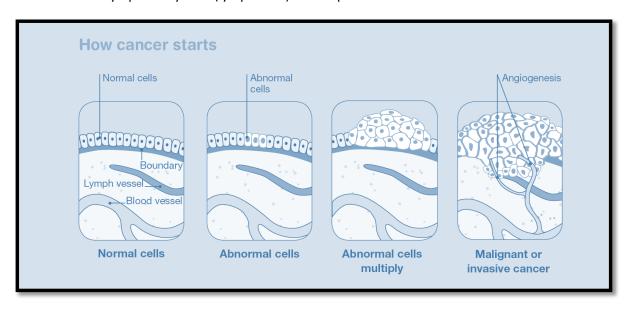


Image Source: Understanding Chemotherapy

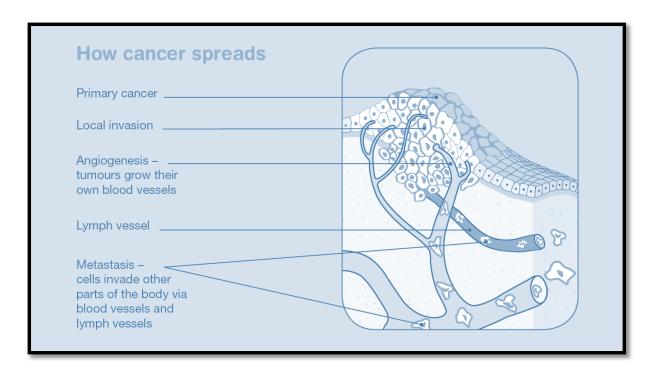


Image Source: <u>Understanding Chemotherapy</u>

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumor is usually named after the organ or type of cell affected. For example, a tumor developing in the lung is called lung cancer. If that tumor then spreads later to the bone or liver, it is called metastatic lung cancer (since the primary tumor started in the lung). We would not call it bone cancer or liver cancer just because it has spread to those organs.

A malignant tumor that has not spread to other parts of the body is called localized cancer. When we say a cancer is "Stage I" or "Stage II," the tumor is usually in its "early stage" and is confined to the organ where it originated. For example, a stage I or stage II breast cancer diagnosis means the tumor is limited to the breast and has not spread. The tumor may spread deeper into the surrounding tissue and can grow its own blood vessels (angiogenesis). It usually involves the surrounding lymph nodes, which are sentinel sites into which the organ drains. Typically, if these nodes are involved, it is called "locally advanced cancer," or Stage III cancer. If the breast cancer also affects the armpit lymph nodes, it would be referred to as "locally advanced breast cancer" or "stage III" breast cancer. The same idea typically applies to other cancers.

# What is Chemotherapy?

Chemotherapy (also called chemo) is a type of cancer treatment that uses drugs to destroy cancer cells. Some of these drugs are obtained from natural sources such as plants, while others are completely developed in the laboratory. There are many types of chemotherapy drugs, which are often used in different combinations and at different strengths. Your medical team may use the term chemotherapy as an umbrella term to describe a combination of medications given together in one treatment, or series of treatments that you may receive. As an example, a treatment for colon cancer called FOLFOX + Avastin, uses three chemotherapy drugs (5FU, Oxaliplatin, Leucovorin) and one lab-engineered biological/ targeted drug called Bevacizumab. This biological drug targets a specific key or receptor on tumor cells called VEGF that helps tumors feed on blood supply. While the whole combination regimen is called your "chemotherapy treatment," it may include not only chemotherapy drugs but also a biological drug that works very differently and in a more targeted fashion.

This type of treatment is becoming more common, replacing old style chemotherapy. In fact, more and more now we combine chemotherapy with biologics and immunotherapy. This enables your oncologist to combine treatments to hit the cancer in all sort of different ways.

# How does chemotherapy work?

Chemotherapy works by stopping or slowing the growth of cancer cells, which grow and divide quickly. It primarily works by destroying tumor cell DNA or accumulating toxins inside tumor cells. But it can also harm healthy cells that divide quickly, such as those that line your mouth and intestines or cause your hair to grow. Damage to healthy cells may cause side effects. Often, side effects get better or go away after chemotherapy is over. Rarely some effects may be long lasting especially in the bone marrow and blood producing cells on the bones. Most chemotherapy drugs enter the bloodstream and travel throughout the body to reach cancer cells in the organs and tissues.

By the time your next treatment starts, your body's normal cells have usually recovered but the cancer cells have not. This is because cancer cells don't repair easily, so they recover more slowly than normal cells. This means that more cancer cells are destroyed with every treatment. Typically, chemotherapy treatments are every 2 to 3 weeks. The time in between treatment is to let your body recover from the last treatment. If the treatments are used more frequently, to hit the tumor harder, growth factors are used to help your blood cells recover. Your blood cells are the most susceptible to the side effects of chemotherapy since they are the second fastest dividing cells in your body after the tumor cells.

# What does chemotherapy do?

Depending on your type of cancer and how advanced it is, chemotherapy can:

**Cure cancer** — Chemotherapy destroys cancer cells to the point that your doctor can no longer detect them in your body and they will not grow back. Some cancers can be cured by chemotherapy on its own, but others require chemotherapy in combination with other treatments, such as surgery or radiation therapy.

Chemotherapy can be given either before or after these other treatments. When used beforehand (as neo-adjuvant therapy), its purpose is to make the cancer smaller so a primary treatment, such as surgery

to remove the tumor, is more effective. If chemotherapy is given after your primary treatment (adjuvant therapy), its aim is to get rid of any remaining cancer cells that may not be seen on scans.

**Control cancer** — If the cancer is too large and can't be cured, chemotherapy can be used to control the cancer's growth for an extended period of time. In this case, chemotherapy can keep cancer from spreading, slow its growth, or destroy cancer cells that have spread to other parts of your body.

**Ease cancer symptoms** — Chemotherapy can also shrink tumors that are causing pain or pressure. When a cancer can't be cured, but causes painful symptoms, chemotherapy or radiation treatment can provide relief. This is also called palliative treatment.

# How is chemotherapy used?

Sometimes, chemotherapy is used as the only cancer treatment. But more often, you will get chemotherapy along with surgery (called concurrent treatment); before surgery (neoadjuvant treatment to shrink the tumor and get it ready for surgery) or adjuvant (after surgery) to prevent recurrence. It can also be used with radiation therapy, targeted therapy, or immunotherapy.

# How does my doctor decide which chemotherapy drugs to use?

# This choice depends on:

- The type of cancer you have. Some types of chemotherapy drugs are used for many types of cancer. Other drugs are used for just one or two types of cancer.
- Whether you have had chemotherapy before.
- Whether you have other health problems, such as diabetes or heart disease.

# Where do I go for chemotherapy?

You may receive chemotherapy during a hospital stay, at home, or in a doctor's office, clinic, or outpatient unit in a hospital (which means you do not stay overnight). No matter where you go for chemotherapy, your doctor and nurse will watch for side effects and make any needed drug changes.

# How often will I receive chemotherapy?

Treatment schedules for chemotherapy vary widely. How often and how long you get chemotherapy depends on:

- Your type of cancer and how advanced it is.
- The goals of treatment (whether chemotherapy is used to cure your cancer, control its growth, or ease the symptoms)
- The type of chemotherapy
- How your body reacts to chemotherapy

You may receive chemotherapy in cycles: A cycle is a period of chemotherapy treatment followed by a period of rest. For instance, you might receive one week of chemotherapy followed by three weeks of rest. These four weeks make up one cycle. The rest period gives your body a chance to build new healthy cells. Your doctor will discuss your treatment plan with you. Sometimes people have

chemotherapy over the course of 6 to 12 months, but it's possible to receive it for a shorter or longer period.

Can I miss a dose of chemotherapy? It is not good to skip a chemotherapy treatment. But sometimes your doctor or nurse may change your chemotherapy schedule due to side effects you are having. If your schedule changes, your doctor or nurse will explain what to do and when to start treatment again. If the delay extends beyond 20% of the expected time frame for treatment, it may have detrimental effects on your outcomes, and it gives tumor time to recover.

# How is chemotherapy given?

Chemotherapy may be given in many ways.

It is most commonly given as a liquid drip into your vein (intravenously). It is usually given through a tube. Depending on the treatment, this could take about 20 minutes or several hours. Sometimes chemotherapy is given continuously over a few days via a portable pump or device.

Before chemotherapy, you may be given medications, so you don't feel sick (anti-nausea or anti-emetic medication). You may also be encouraged to drink several glasses of water during the treatment.

You will be in a room or a lounge area with other patients when you are having chemotherapy. You are usually able to walk around the lounge during the treatment, for example if you need to go to the toilet.

The doctor will typically examine you and approve your treatment before every treatment. The nurses will assess you before chemotherapy and monitor you during and after the treatment. They will let you know when you are able to go home after receiving treatment.

Your nurses will also talk to you about managing side effects and tell you about any medication you need to take at home.

The different ways treatments are given are:

- Intravenous (IV): The typical way of giving cancer treatments. Chemotherapy goes directly into a vein.
- **Oral**: The chemotherapy comes in pills, capsules, or liquids that you swallow. Some people take chemotherapy tablets or capsules at home. Your doctor, nurse or pharmacist will tell you how and when to take them, how to handle the medication safely, and what side effects to expect.
- **Topical:** The chemotherapy comes in a cream that you rub onto your skin. Some skin cancers are treated by using a chemotherapy cream that is applied directly to the skin.
- **Injections:** Less commonly, chemotherapy can be injected using a needle into different parts of the body:
  - Intramuscular into a muscle, usually in your buttock or thigh
  - Subcutaneous just under the skin
  - o Intrathecal into the fluid around the spine (also known as a lumbar puncture)
  - o Intra-arterial into an artery, for example, the hepatic artery in the liver
  - Intraperitoneal into your abdominal area (peritoneum)
  - o Intrapleural into the outer lining of the lungs
  - o Intravesical into the bladder

- o Intralesional into the tumor (this method is rare).
- Chemotherapy wafers: Some people who have surgery for a brain tumor (craniotomy) will have small, dissolvable gel wafers of chemotherapy placed directly into the tumor site during the operation.
- **High-dose chemotherapy:** This is a treatment given as part of a bone marrow or peripheral blood stem cell transplant for blood cancers, such as leukemia or lymphoma. The high-dose chemotherapy kills off all the cancer cells in the blood before the new, healthy cells are transplanted a day or two later. This may be done at a large academic center if you are receiving a bone marrow transplant.
- **Chemoembolization:** Used for liver cancer or some types of cancer that have spread to the liver, chemoembolization is a procedure of injecting chemotherapy directly into the blood vessels supplying a tumor. The chemotherapy is mixed with tiny spheres that block the vessels and stop the tumor getting nutrients and oxygen.
  - **Chemoradiation:** Giving chemotherapy together with radiotherapy is used for some cancers, such as head and neck cancer or rectal cancer. The chemotherapy is given during the course of radiotherapy to make the radiotherapy more effective.

While IV chemotherapy is the most used technique of giving therapy at NMHOS, you may have treatment given through catheters or ports, sometimes with the help of a pump.

- Ports. A port is a small, round disc made of plastic or metal that is placed under your skin. A
  catheter connects the port to a large vein, most often in your chest. Your nurse can insert a
  needle into your port to give you chemotherapy or draw blood. If you are receiving
  chemotherapy treatments over the course of more than one day, this needle can be left in
  place. Be sure to watch for signs of infection around your port such as redness or discomfort.
- 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 your body. Most people can carry these pumps with them. Internal pumps are placed under your skin during surgery.

Less often, patients receive chemotherapy through a thin needle placed in a vein on your hand or lower arm. Your nurse will put the needle in at the start of each treatment and remove it when treatment is over. Let your doctor or nurse know right away if you feel pain or burning while you are getting IV chemotherapy. At NMHOS we avoid using irritant chemotherapies through small veins and prefer using larger convenient port access.

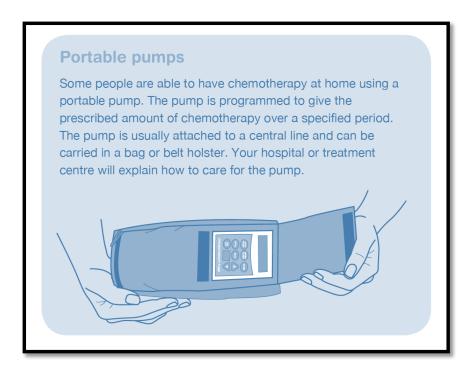


Image Source: Understanding Chemotherapy

# Can you have chemotherapy during pregnancy?

Being diagnosed with cancer during pregnancy is rare – about one in 1000 pregnant women are affected.

It is possible for some pregnant women to have chemotherapy. Your medical team will discuss all of the available treatment options with you. Their recommendations will be based on the type of cancer you have, its stage, the other treatment options, and how to avoid harming your developing baby. Sometimes chemotherapy or other treatment can be delayed until after the baby's birth.

If you receive chemotherapy during pregnancy, your doctor will probably advise you to stop having treatments at least 3 to 4 weeks before your delivery date. This is because chemotherapy increases your risk of bleeding or getting an infection during the birth. Stopping chemotherapy allows your body time to recover from the side effects.

Researchers are currently doing long-term studies on women and children to explore this issue further. It is known that giving chemotherapy in the first trimester (12 weeks) increases the risk of birth defects. However, some studies on children who were exposed to chemotherapy in the womb during the second and third trimesters show that chemotherapy did not affect their development.

Different chemotherapy drugs may affect a developing baby in different ways. For example, chemotherapy may cause premature delivery. Pre-term babies often have other health problems, such as respiratory problems and delayed development.

Your doctor can talk in detail about your specific situation and what is best for your health and your unborn baby.

#### Home Safety after Chemotherapy Treatments

After receiving chemotherapy, you and your caregivers need to take special care to prevent contact with your body fluids. These fluids include urine, stools, sweat, mucus, blood, vomit, and those from sex. These are just a few suggestions you and your caregivers may hear from your doctor or nurse:

- Don't crush, cut or chew chemotherapy pills
- After using the toilet, remember to close the lid and flush twice.
- When urinating on the toilet, remain seated (even if you usually stand).
- Wash your hands with soap and water after using the restroom.
- Avoid pregnancy during chemotherapy
- Clean any splashes from the toilet with bleach wipes.
- Use gloves when handling any body fluids and wash your hands thoroughly after removing the gloves.
- If incontinence is an issue, wear disposable pads or diapers and use gloves to handle these items.
- Wash any linens soiled with body fluids separately from the rest of your laundry.
- Store chemotherapy tablets in a separate pill organizer, away from the reach of children. Seal empty tablet containers in a plastic box and return to pharmacy
- Always use condoms during sex.

Depending on the drugs you receive over the course of your chemotherapy, the length of time that you and your caregivers need to follow these guidelines might differ. Your doctor or nurse will tell you how long you and your caregivers need to practice these measures.

# **Smoking and chemotherapy**

If you smoke, it's best to try to quit, especially while you are having chemotherapy.

Research shows that ex-smokers and people who have never smoked have better survival rates from cancer than smokers. Recent studies also suggest that smoking during chemotherapy may reduce the effectiveness of the treatment

# How will I feel during chemotherapy?

Chemotherapy affects people in different ways. How you feel depends on how healthy you are before treatment, your type of cancer, how advanced it is, the kind of chemotherapy you are getting, and the dose. Doctors and nurses cannot know for certain how you will feel during chemotherapy.

There are many ways to manage chemotherapy side effects. See sections of this guide about side effects.

# Can I work during chemotherapy?

Many people can work during chemotherapy, as long as they match their schedule to how they feel. Whether or not you can work may depend on what kind of work you do. If your job allows, you may want to see if you can work part-time or work from home on days you do not feel well.

Many employers are required by law to change your work schedule to meet your needs during cancer treatment. Talk with your employer about ways to adjust your work during chemotherapy. You can learn more about these laws by talking with a social worker.

# Can I take over-the-counter and prescription drugs while I get chemotherapy?

This depends on the type of chemotherapy you get and the other types of drugs you plan to take. Take only drugs that are approved by your doctor or nurse. Tell your doctor or nurse about all the over the counter and prescription drugs you take, including laxatives, allergy medicines, cold medicines, pain relievers, aspirin, and ibuprofen. Some multivitamins and herbal preparations prevent development of free oxygen radicals and this can interfere with your chemotherapy's ability to kill cancer cells.

Bring a list of all the prescription medications, over-the-counter medications and whatever vitamins and herbal supplements you are taking. Everything could have an impact on your treatment. If possible, bringing all your pill bottles is ideal.

Your doctor or nurse needs to know:

- The name of each drug
- The reason you take it
- How much you take
- How often you take it.

# Can I take minerals, dietary supplements, or herbs while I get chemotherapy?

Some of these products can change how chemotherapy works. For this reason, it is important to tell your doctor or nurse about all the vitamins, minerals, dietary supplements, and herbs that you take before you start chemotherapy. During chemotherapy, talk with your doctor before you start any of these products.

# How will I know if chemotherapy is working?

Your doctor will give you physical exams and medical tests (including blood tests, CT Scans, PET Scans or tumor marker blood tests) and will ask you how you are feeling. All of this information will be used to determine the effectiveness of the chemotherapy.

You cannot tell if chemotherapy is working based on its side effects. Some people think that severe side effects mean that chemotherapy is working well, or that no side effects mean that chemotherapy is not working. The truth is that side effects have nothing to do with how well chemotherapy is fighting your cancer.

If tests show that the cancer has shrunk and is unable to be detected, this may be called remission, which means there is no evidence of active cancer. Although the cancer is gone, your doctor will monitor you for several months or years before you are considered cured. This is because cancer can sometimes come back in the same place or grow in another part of the body.

If you are having adjuvant chemotherapy to prevent cancer coming back, it is not possible to tell if this treatment has been effective for some years.

If chemotherapy is being given as palliative treatment, the relief of your symptoms will show if the treatment is working.

# What should I do while getting my treatments?

You may spend a lot of time waiting while you receive chemotherapy treatment. There are several time-consuming steps to ensure your chemotherapy is appropriate, timely and accurate. You may experience delays due to safety checks, emergencies or the workload of the treatment center. While we try to respect your time and keep things moving, some delays are unavoidable. We recommend you bring water and snacks with you in anticipation of these long delays.

To pass the time, you could try any of the following activities:

- Read a book or magazine, or listen to music
- Complete a crossword or other puzzle
- Chat with a companion
- Use a laptop, tablet or other electronic device
- Write or draw in a journal
- Meditate or practice relaxation techniques

At first, you may feel uncomfortable being around people who are sick because of cancer or their treatment. You may not identify with them. However, many people find support from others who are receiving chemotherapy at the same time as them.

While you may bring a friend or family member with you to your treatments, please understand we do have limited seating, and may not have space for more than one visitor per patient.

# What are Biologics or Targeted therapies?

Other drugs, called targeted therapies, may be used instead of or together with chemotherapy to target particular types of cancer cells while minimizing harm to healthy cells. Drugs whose pharmacological name ends in -mabs are typically proteins that have been engineered in the lab to bind targets on cancer cells and help either kill the tumor directly or more often by using the body's immune system to attack the marked cell.

Targeted therapies have different actions to help destroy or stop the growth of cancer cells. Not all cancers respond to targeted therapies, and some of these therapies are only available in clinical trials.

<u>Side Effects:</u> You may have side effects that are caused by the targeted therapy rather than by the chemotherapy. Side effects depend on the medication used. Some typical effects include fevers, allergic

reactions, rashes, diarrhea and blood pressure changes. Some targeted therapies can affect the way your heart works.

Rarely, some targeted therapies may cause life-threatening side effects. Your doctor will discuss this with you.

| Drug Inerapies: Several     | <b>Drug Therapies:</b> Several different types of targeted therapies are used to treat cancer |  |
|-----------------------------|---|--|
|                             |   |  |
| Angiogenesis inhibitors     | For cancer cells to grow and spread to other areas of the body, they need to                  |  |
|                             | make their own blood vessels. Drugs known as angiogenesis inhibitors                          |  |
|                             | attack developing blood vessels so that the cancer can't grow and spread.                     |  |
|                             |   |  |
| Tyrosine kinase             | These drugs may block certain proteins or enzymes that tell cancer cells to                   |  |
| inhibitors                  | grow. They are sometimes called small molecule drugs.   |  |
|                             |   |  |
| Apoptosis-inducing          | Apoptosis means cell death. These drugs target the part of the cancer cell                    |  |
| drugs                       | that tells it when to die.  |  |
|                             |   |  |
| Immunotherapies: Immu       | unotherapies (also called biological therapies) strengthen the immune system                  |  |
| so it finds and kills cance | r cells.  |  |
| Active                      | Stimulate your immune system to fight infection and disease. You might be                     |  |
| immunotherapies             | given a vaccine to make your body produce antibodies to fight cancer.                         |  |
|                             |   |  |
| Passive                     | These use man-made (synthetic) antibodies developed in a laboratory to                        |  |
| immunotherapies             | get your immune system to fight cancer cells.   |  |
| ,                           | , ,   |  |
| Receptor blocking           | Blocking receptors can assist with cancer cell death in some cancers. For                     |  |
| agents                      | example, female hormones in breast cancer or male hormones in prostate                        |  |
|                             | cancer.   |  |
|                             |   |  |
| L                           |   |  |

## **Key points**

- Chemotherapy is most commonly given via a tube into a vein (intravenously).
- Usually people will have chemotherapy as an outpatient at a hospital or clinic, but sometimes they can have it at home using a portable pump.
- Oral chemotherapy as tablets or capsules is also common.
- Some chemotherapy is specific for some types of cancers: e.g. cream for skin cancer, chemoembolization for liver cancer, or wafers for brain cancer.
- You may have one drug or a combination of drugs. Different drugs and combinations are effective for different cancer types.
- Chemotherapy can be harmful to others if they are exposed to it. For this reason, nurses and doctors wear protective clothing when giving chemotherapy. However it is safe to be around family members and friends, including children and pregnant women.

- Your medical team will advise you about taking precautions at home to make sure your family members don't come into contact with your body fluids, such as urine or vomit, as the drugs may be passed into them. You should also handle medication with care.
- Drugs known as targeted therapies may be used instead of or with chemotherapy to target particular types of cancer cells.
- You will see a range of health professionals when you have chemotherapy. This may include a medical oncologist or a hematologist, nurses and allied health professionals.

# Cost of Cancer Treatments

How much does chemotherapy cost? It can be difficult to determine, but it usually depends on certain factors:

- The types and doses of chemotherapy used
- How long and how often chemotherapy is given
- Whether you get chemotherapy at home, in a clinic or office, or during a hospital stay
- The part of the country where you live

Does my health insurance pay for chemotherapy? We recommend you talk with your health insurance company about your coverage. Questions to ask may include:

- What will my insurance pay?
- Do I, or does my doctor's office, need to call my insurance company before each treatment for it to be covered?
- What do I have to pay for?
- Can I see any doctor?
- Do I need to choose from a list of preferred providers?
- Do I need a written referral to see a specialist?
- Is there a co-pay (money I have to pay) each time I have an appointment?
- Do I have a deductible/coinsurance (certain amount I need to pay) to meet before my insurance pays?
- Where should I get my prescription medications?
- Does my insurance pay for all my tests and treatments, whether I am an inpatient or outpatient?
- How can I work with my insurance plan?

Read your insurance policy before treatment starts to find out what your plan will and will not pay for. Keep records of all your treatment costs and insurance claims. Send your insurance company all the paperwork it asks for. This may include receipts from doctors' visits, prescriptions, and lab work. Be sure to keep copies for your own records. As needed, ask for help with the insurance paperwork. If your insurance does not pay for something you think it should, find out why the plan did not pay.

You may talk with the financial staff about what to do next. They may suggest ways to appeal the decision or other actions to take. Our financial staff are always available to help guide and answer your

questions related to your care and treatment in our office. They will be sure that the focus remains on your health and your treatment, not your bills.

Our team is there to assist you and answer those questions about bills and insurance coverage. We want you to know that we understand that you may have questions about your cancer diagnosis, and finances. We work with charities, drug manufacturer patient assistance programs and co-pay cards, as well as foundations with financial assistance, which may help cover your treatment costs. Please ask to speak to one of our office financial representatives to assist you.

# Tips for Meeting with Your Doctor or Nurse

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 talk 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 to help 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.

Find out how to contact your doctor or nurse in an emergency. This includes who to call and where to go. Write important phone numbers in the spaces provided on the inside front cover of this book.

# Distress Management

It is normal to have a wide range of feelings while going through chemotherapy. After all, living with cancer and going through treatment can be stressful. Your role at home, school, and/or work can be affected. Everyday stress can make coping with your treatment more difficult but chronic stress may weaken your immune system, causing other health problems and decreasing feelings of well-being. You may also experience fatigue, which can make it harder to cope with your feelings. It is important to recognize changes and get help when needed.

At some point during chemotherapy, you may feel:

- Frustration
- Helplessness
- Loneliness
- Anxiety (or worry)
- Sadness
- Fear
- Anger

At NMHOS we have a distress management plan in place to help us take care of those who need help in relieving psychological distress. Understand that when we are treating the "whole person" this includes your emotional and mental health as well. A simple questionnaire called the Distress Thermometer will help your cancer care team identify risk factors that point towards coping difficulties. If these challenges are identified, you may be referred to one of our behavioral health providers at Artesia General Hospital to help get your psychological needs met while attending the immediate cancer treatment.

When you meet a behavioral health provider, they will first conduct a diagnostic interview called a psychiatric evaluation. This visit focuses on your emotional distress and risk factors involved that may be barriers to your treatment. They will also be identifying your strengths (that you may not even recognize) that will be utilized moving forward. At the conclusion of your visit they will discuss with you what interventions may be most effective in your mental health care.

You may be asked to participate in counseling and psychoeducational services that will help identify positive coping mechanisms for stress management, mitigate risky behaviors around smoking and/or substance use, and promote an overall healthy lifestyle. Sometimes, if more serious, medication may be prescribed to alleviate the distress you are carrying. These interventions can ultimately provide you a better quality of life and survivorship post-cancer treatment.

# What are some things I can do right now to cope with my feelings during chemotherapy?

Relax. Find some quiet time and think of yourself in a favorite place. Breathe slowly or listen to soothing music. This may help you feel calmer and less stressed. Next time you are taking a walk or even sitting in a waiting room try it out. For more on relaxation exercises, visit the <u>Learning to Relax page</u> on the National Cancer Institute's web site at: <u>www.cancer.gov/about-cancer/coping/feelings/relaxation</u>.

Exercise. Many people find that light exercise helps them feel better. There are many ways for you to exercise, such as walking, riding a bike, and doing yoga. Talk with your doctor or nurse about ways you can exercise.

Talk with others. Talk about your feelings with someone you trust. Choose someone who can focus on you, such as a close friend, family member, chaplain, nurse, or social worker. You may also find it helpful to talk with someone else who is going through chemotherapy.

Reduce your stress. Avoid scheduling conflicts by using a day planner or your phone to keep track of your appointments and other obligations. Be aware of your limits and learn to say "no." If you don't have the time or energy, its ok to decline when asked to take on new tasks. Ask for help from your friends, family, and coworkers when you need it. Prioritize your tasks by making a list of the most important things listed at the top and begin your focus there. Get help with financial problems by talking with an oncology social worker or a financial advisor who knows about cancer related insurance and financial matters. And lastly, concentrate your efforts on things you can control and remain flexible. For more tips on managing stress go to <a href="https://www.cancer.net/coping-with-cancer/managing-emotions/managing-stress">www.cancer.net/coping-with-cancer/managing-emotions/managing-stress</a>.

Join a support group. Cancer support groups provide support for people with cancer. These groups allow you to meet others with the same problems. You will have a chance to talk about your feelings and listen to other people talk about theirs. You can find out how others cope with cancer, chemotherapy, and side effects. Your doctor, nurse, or social worker may know about support groups near where you live. Some support groups also meet online (over the Internet), which can be helpful if you cannot travel.

Talk to your doctor or nurse about things that worry or upset you. You may want to ask about seeing a behavioral health provider at Artesia General Hospital. Your doctor may also suggest that you take medication if you find it very hard to cope with your feelings.

Ways to learn more to learn more about coping with your feelings and relationships during cancer treatment, read <u>Taking Time</u>: <u>Support for People with Cancer</u>, a booklet from the National Cancer Institute, available at <u>www.cancer.gov/publications/patient-education/taking-time</u>

Cancer Support Community Dedicated to providing support, education, and hope to people affected by cancer. Call: 1-888-793-9355 Visit: <a href="http://www.cancersupportcommunity.org">http://www.cancersupportcommunity.org</a>
E-mail: help@cancersupportcommunity.org

CancerCare, Inc. Offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Call: 1-800-813-HOPE (1-800-813-4673) Visit: <a href="http://www.cancercare.org">http://www.cancercare.org</a> E-mail: <a href="mailto:info@cancercare.org">info@cancercare.org</a>

# **About Side Effects**

#### What are side effects?

Side effects are problems caused by your cancer treatment. Some common side effects from chemotherapy include fatigue, nausea, vomiting, decreased blood cell counts, hair loss, mouth sores, and pain. If the side effects are severe, your treatment team may adjust your dose or hold your next treatment.

Targeted biologicals can cause side effects that differ from those of chemotherapy. These can include hypertension, skin rash, hand foot syndrome, diarrhea, and fatigue.

Immunotherapy side effects typically relate to overactivation of immune cells that cause collateral damage to normal tissues and cause 'itis' like colitis (inflammation of bowel wall causing diarrhea), thyroiditis (inflammation of thyroid causing low thyroid levels), pneumonitis (inflammation of lung causing shortness of breath or cough), hepatitis (liver inflammation); inflammation and infiltration of these organs by activated T cell (immune cells) can cause organ specific symptoms. These are usually temporary and can subside with steroids and or holding the treatment.

#### What causes side effects?

Chemotherapy is designed to kill fast-growing cancer cells. But it can also affect healthy cells that grow quickly. These include cells that line your mouth and intestines, cells in your bone marrow that make blood cells, and cells that make your hair grow. Chemotherapy causes side effects when it harms these healthy cells.

# Will I get side effects from chemotherapy?

You may have a lot of side effects, some, or none at all. This depends on the type and amount of chemotherapy you get and how your body reacts. Before you start chemotherapy, talk with your doctor or nurse about which side effects to expect.

# How long do side effects last?

How long side effects last depends on your health and the kind of chemotherapy you get. Most side effects go away after chemotherapy is over. But sometimes it can take months or even years for them to go away.

Sometimes, chemotherapy causes long-term side effects that do not go away. These may include damage to your heart, lungs, nerves, kidneys, or reproductive organs. Some types of chemotherapy may cause a second cancer years later. Ask your doctor or nurse about your chance of having long-term side effects.

What can be done about side effects?

Doctors have many ways to prevent or treat chemotherapy side effects, and to help you heal after each treatment. Talk with your doctor or nurse about which side effects you might expect and what you can

do about them. Make sure to let your doctor or nurse know about any changes you notice—they may be signs of a side effect.

It can be useful to record information about your chemotherapy treatment in one place, like a **chemotherapy diary**. This makes it easier to recall details about when you experienced side effects, how long they lasted and what helped to reduce them. Some people use a notebook or a diary, while others prefer technology such as a smartphone. You can help your treatment team by taking note of dates, times and what symptoms you experienced. Sharing this information with your doctors and nurses will allow them to give you more accurate suggestions for dealing with side effects, or for adjusting your treatment if appropriate.

Remember you may have only a few of these side effects, most of them or none. Most patients experience at least some mild side effects. Don't get anxious about these. Once you know what to expect after the first cycle, this booklet along with your cancer team at NMHOS will educate and arm you to manage those effects so you can continue to receive treatment and maintain a healthy quality of life.

## **Key points**

- Many people experience side effects from chemotherapy. Side effects are caused when the chemotherapy damages rapidly dividing healthy cells.
- Most side effects are temporary and gradually go away after you've finished treatment.
- Common side effects include feeling tired, loss of appetite, nausea, mouth sores, digestive problems, hair loss and skin problems.
- You may also have nerve and muscle effects, hearing changes and a reduced ability to concentrate or remember things.
- You will also be at an increased risk of infections. This is because chemotherapy can reduce your levels of white blood cells, which are necessary for fighting infections.
- You may have sexuality and fertility problems, such as reduced sexual desire (libido) or loss of fertility. You might be able to store eggs (ova), embryos or sperm for use at a later date. Talk to your doctor about these issues.
- Your doctor or nurse will advise you on how to cope with any side effects. You may be given medication or suggestions for eating, drinking and looking after yourself.
- If you have any side effects that weren't discussed with you before treatment, let your health care team know so that they can help you.
- It may be helpful to record your symptoms, when they occurred and what you did to relieve them. Show your notes to your doctor or nurse so they are aware of how the chemotherapy is affecting you.

# What Foods to Eat and What to Avoid

Cancer and cancer treatments can cause many problems that affect how well you can eat and drink. Here are some of the more common problems and tips on how to deal with them. Always tell your cancer care team about any problems you have. There are often things that can be done to treat the problem or keep it from getting worse.

Cancer and its treatment can cause changes in your eating habits and your desire to eat. Not eating can lead to weight loss, and this can cause weakness and fatigue. Eating as well as you can is an important part of taking care of yourself. Treatment related side effects like pain, nausea, and constipation can also cause loss of appetite. Managing these problems may help you eat better.

#### What to do

- Eat several snacks throughout the day, rather than 3 large meals.
- Avoid liquids with meals or take only small sips of liquids to keep from feeling full early (unless you need liquids to help swallow or for dry mouth). Drink most of your liquids between meals.
- Make eating more enjoyable by setting the table with pretty dishes, playing your favorite music, watching TV, or eating with someone.
- Be as physically active as you can. Start off slowly and increase your activity over time as you feel stronger. Sometimes a short walk an hour or so before meals can help you feel hungry.

Pain medicines, changes in your eating habits, and being less active can cause your bowels to move less often and stools to become harder to pass (constipation). If you're constipated, try eating high-fiber foods. Also drink extra fluids during the day, eat at regular times, and try to increase your physical activity, if possible.

#### What to do

- Try to have a bowel movement at the same time each day.
- Drink 8 to 10 cups of liquid each day, if it's OK with your doctor. Try water, prune juice, warm juices, teas, and hot lemonade. (A hot beverage may help to stimulate a bowel movement.)
- Use laxatives only as directed by your cancer care team. Contact your team if you haven't had a bowel movement for 3 days or longer.
- Ask your dietitian to recommend a high-calorie, high-protein, fiber-containing liquid supplement if you need more of these.
  - Limit drinks and foods that cause gas if it becomes a problem.

| Foods that might cause gas Limit these foods if gas becomes a problem. |                          |                |
|--|--------------------------|----------------|
| Apples (raw), apple juice  | Cucumbers                | Peppers        |
| Asparagus  | Eggs                     | Pickles        |
| Avocado  | Fish                     | Radishes       |
| Dried beans and peas   | Kohlrabi                 | Rutabaga       |
| Beer   | Lentils                  | Sauerkraut     |
| Broccoli   | Melons                   | Spicy foods    |
| Brussels sprouts   | Milk                     | Spinach        |
| Cabbage  | Mushrooms                | String beans   |
| Cauliflower  | Mustard                  | Strong cheese  |
| Collards   | Nuts                     | Sweet potatoes |
| Corn   | Onions, leeks, scallions | Turnip Greens  |

| Foods to help with side effects  Clear liquid diet: This will help when swallowing is extremely difficult and radiation to the head and neck or food pipe is causing inflammation and mucositis. |  |  |
|--|--|--|
| Soups  | Clear chicken bouillon; clear, fat-free broth; consommé drinks   |  |
| Drinks   | Clear apple juice, clear carbonated beverages, fruit-flavored drinks, fruit punch, sports drinks (avoid sugary ones), water (or flavored water), caffeine-free tea, coconut water (great source of electrolytes like potassium)                  |  |
| Sweets   | Fruit ices popsicles made without fruit or milk, gelatin, honey (Manuka honey is expensive but could come with added bactericidal benefit), jelly, popsicles   |  |
| <b>Liquid /soft diet</b> : Thicker having more than just cle   | in consistency and usually more calories, when you are on your way to ear liquid   |  |
| Soups  | Bouillon, broth, cheese soup, soup that has been strained or put through a blender, soup with pureed potatoes, tomato soup   |  |
| Drinks   | Carbonated beverages, coffee, eggnog (pasteurized and alcohol free), fruit drinks, milk (lactose free preferred), milkshakes, smoothies, sports drinks, herbal teas, tomato juice (consider diluting if too acidic), vegetable juice (V8), water |  |

| Fats        | Ghee, grass fed butter, cream, sour cream  |
|-------------|--|
| Desserts    | Custard (soft or baked), frozen yogurt, fruit purees that are watered down, gelatin, honey, ice cream with no chunks, such as nuts or cookie pieces, gelato, pudding, diluted kefir $(1/3^{rd} \text{ kefir }, 2/3^{rd} \text{ water add salt or sugar to taste})$ |
| Supplements | Oatmeal, Boost, Ensure etc.  |

| Foods and drinks that are high in calories and protein This partial list may help for when you do not feel like eating |   |
|--|---|
| Soups  | Cream soups; soups with lentils, peas, or beans, such as garbanzo, pinto, black, red, and kidney  |
| Drinks   | Instant breakfast drinks, milkshakes, smoothies, whole milk   |
| Main Meals and other foods   | Beef; butter, margarine, or oil added to food; cheese; chicken; cooked dried peas and bean, such as lentils, garbanzo, pinto, black, red, and kidney; cottage cheese; cream cheese; croissants; deviled ham; eggs, fish; nuts, seeds, and wheat germ; peanut butter; sour cream |
| Sweets   | Custards, soft or baked; frozen yogurt; ice cream; muffins; pudding; yogurt, plain or vanilla   |
| Replacements and<br>Supplements  | Liquid meal replacements; powdered milk added to foods, such as pudding, milkshakes, and scrambled eggs   |

| High-Fiber foods This partial list may help if you have difficulty passing bowel movements |   |
|--|---|
| Main meals and other foods   | Bran muffins; bran or whole-grain cereals; brown or wild rice; cooked dried peas and beans, such as lentils, garbanzo, pinto, black, red, and kidney; whole-wheat bread; whole-wheat pasta        |
| Fruits and vegetables  | Dried fruit, such as apricots, dates, prunes, and raisins; fresh fruit, such as apples, blueberries, and grapes; raw or cooked vegetables, such as broccoli, corn, green beans, peas, and spinach |
| Snacks   | Granola, nuts, popcorn, seeds (such as pumpkin or sunflower), trail mix   |

| Low-Fiber foods This partial list may help if you have loose or watery bowel movements: |   |
|---|---|
| Main meals and other<br>foods   | Chicken or turkey, skinless; cooked refined cereals; cottage cheese; eggs; fish; noodles; potatoes, baked or mashed without the skin; white bread; white rice |
| Fruits and vegetables   | Asparagus; bananas; canned fruit, such as peaches, pears, and applesauce; clear fruit juice; vegetable juice  |
| Snacks  | Angel food cake; gelatin; saltine crackers; sherbet or sorbet; yogurt, plain or vanilla   |

| Foods that are easy on a sore mouth This partial list may help if your mouth or throat are sore: |  |
|--|--|
| Main meals and other foods   | Baby food, cooked refined cereals, cottage cheese, eggs (soft boiled or scrambled), macaroni and cheese, mashed potatoes, pureed cooked foods, soups       |
| Sweets   | Custards, fruit (pureed or baby food), gelatin, ice cream, milkshakes, puddings, smoothies, soft fruits (bananas or applesauce), yogurt (plain or vanilla) |

| Foods that are easy on the stomach This partial list may help if you feel queasy or have trouble keeping food down: |   |  |  |
|---|---|--|--|
| Main meals and other<br>foods   | Baby food, cooked refined cereals, cottage cheese, eggs, macaroni and cheese, mashed potatoes, pureed cooked foods, soups                               |  |  |
| Sweets  | Custards, fruit (pureed or baby food), gelatin, ice cream, milkshakes, puddings, smoothies, soft fruits (bananas or peaches), yogurt (plain or vanilla) |  |  |

# Neutropenic Diet (neutropenic – low white count; weakened immune system)

Cancer and its treatment can weaken your body's immune system by affecting the blood cells that protect us against disease and germs. As a result, your body won't be able to fight infection, foreign substances and disease as well as a healthy person's body can. When your absolute neutrophil count is under 1000, you will be contacted and asked to take precautions to avoid food-borne infections.

# Here are some tips on how to help protect yourself

## Food-handling tips

- Wash your hands with warm, soapy water for 20 seconds before and after preparing food and before eating.
- Refrigerate foods at or below 40° F.
- Keep hot foods hot (warmer than 140° F) and cold foods cold (cooler than 40° F).
- Thaw meat, fish, or poultry in the microwave or refrigerator in a dish to catch drips. Do not thaw at room temperature.
- Use defrosted foods right away, and do not refreeze them.
- Rinse leaves of leafy vegetables one at a time under running water.
- Use different utensils for stirring foods and tasting them while cooking. Do not taste the food (or allow others to taste it) with any utensil that will be put back into the food.
- Throw away eggs with cracked shells.
- Throw out foods that look or smell strange. Never taste them!

#### Do not cross-contaminate

- Use a clean knife to cut different foods.
- In the refrigerator, store raw meat sealed and away from ready-to-eat food.
- Keep foods separated on the countertops. Use a different cutting board for raw meats.
- Clean counters and cutting boards with hot, soapy water, or you can use a fresh solution made of 1 part bleach and 10 parts water. Moist disinfecting wipes may be used if they're made for use around food.
- When grilling, always use a clean plate for the cooked meat. Cook foods well
- Put a meat thermometer into the middle of the thickest part of the food to test for doneness. Test a thermometer's accuracy by putting it into boiling water. It should read 212° F.
- Cook meat until it is no longer pink, and the juices run clear. The only way to know for sure that meat has been cooked to the right temperature is to use a food thermometer. Meats should be cooked to 160° F and poultry to 180° F.

#### Grocery shopping

- Do not use damaged, swollen, rusted, or deeply dented cans. Be sure that packaged and boxed foods are properly sealed.
- Choose unblemished fruits and vegetables.
- Do not eat deli foods. In the bakery, avoid unrefrigerated cream- and custard-containing desserts and pastries.

- Do not eat foods that are bought from self-serve or bulk containers.
- Do not eat yogurt and ice cream products from soft-serve machines.
- Do not use cracked or unrefrigerated eggs.
- Get your frozen and refrigerated foods just before you check out at the grocery store, especially during the summer months.
- Refrigerate groceries right away. Never leave food in a hot car.

# Dining out

- Eat early to avoid crowds.
- Ask that food be prepared fresh in fast-food restaurants.
- Ask for single-serving condiment packages, and avoid self-serve bulk condiment containers.
- Do not eat from high-risk food sources, including salad bars, delicatessens, buffets and smorgasbords, potlucks, and sidewalk vendors.
- Do not eat raw fruits and vegetables when eating out.
- Ask if fruit juices are pasteurized. **Avoid "fresh-squeezed"** juices in restaurants.
- Be sure that utensils are set on a napkin or clean tablecloth or placemat, rather than right on the table.
- If you want to keep your leftovers, ask for a container, and put the food in it yourself rather than having the server take your food to the kitchen to do this.

| Tips for when your white blood cell count is low + |   |  |  |  |
|--|---|--|--|--|
|  | Recommended   | Avoid (do not eat)   |  |  |
| Meat, poultry, fish, tofu, and nuts                | Ensure all meats, poultry and fish are cooked thoroughly.   | Raw or lightly cooked fish, shellfish, lox, sushi or sashimi   |  |  |
|  | Use a food thermometer to be sure that meat and poultry reach the proper temperature when cooked. | Raw nuts or fresh nut butters  |  |  |
|  | Vacuum-sealed nuts and shelf-<br>stable nut butters   |  |  |  |
| Eggs   | Cook eggs until the yolks and whites are solid, not runny.  | Raw or soft-cooked eggs. This includes over-easy, poached, soft-boiled, and sunny side up.                           |  |  |
|  | Pasteurized eggs or egg custard   |  |  |  |
| Milk and dairy products                            | Only pasteurized milk, yogurt, cheese, or other dairy products                                    | Soft, mold ripened or blueveined cheeses, including Brie, Camembert, Roquefort, Stilton, Gorgonzola, and blue cheese |  |  |
|  |   | Mexican-style cheeses, such as queso blanco fresco, since they   |  |  |

|                                |  | are often made with unpasteurized milk   |
|--------------------------------|--|--|
| Breads, cereal, rice and pasta | Breads, bagels, muffins, rolls, cereals, crackers, noodles, pasta, potatoes and rice are safe to eat as long as they are purchased as wrapped, prepackaged items, not sold in self-service bins. | Bulk-bin sources of cereals, grains and other foods  |
| Fruits and vegetables          | Raw vegetables and fruits and fresh herbs are safe to eat if washed under running water and lightly scrubbed with a vegetable brush.   | Fresh salsas and salad dressings found in the refrigerated section of the grocery store. Choose shelf-stable salsa and dressings instead. Any raw vegetable sprouts (including alfalfa, radish, broccoli or mung beat sprouts) |
| Desserts and sweets            | Fruit pies, cakes and cookies; flavored gelatin; commercial ice cream, sherbet, sorbet and popsicles; sugar; commercially prepared and pasteurized jam, jelly, preserves, syrup and molasses     | Unrefrigerated, cream-filled pastry products; raw honey or honeycomb. Select a commercial, grade-A, heat-treated honey instead   |
| Water and beverages            | Drink only water from city or municipal water services or commercially bottled water; pasteurized fruit and vegetable juices, soda, coffee and tea.  | Water straight from lakes, rivers, streams or springs; well water (unless you check with your cancer care team first); unpasteurized fruit and vegetable juices  |

<sup>+</sup> Adapted from Grant BL, Bloch AS, Hamilton KK, Thomson CA. *American Cancer Society Complete Guide to Nutrition for Cancer Survivors, 2<sup>nd</sup> Edition.* Atlanta, GA: American Cancer Society; 2010.

# Side Effects with Cancer Treatments

Keeping a positive outlook is proven to help with stress management, but when someone says to "think positive" or "be optimistic" during a time such as cancer, it can be much easier said than done. There is nothing worse than a person who has lost their joy on life.

Going through cancer isn't all rainbows and butterflies, and the "fight" doesn't always look glamorous. Just like with life some days will be more of a struggle than others and some days will bring a tenderness and peace that reminds us of the pleasures of life, living and family.

Try not to keep your mind occupied with your cancer or its treatment. An occupied mid is missing the present and you have a life to live and family to enjoy. Most of our patients tell us that their cancer diagnosis taught them how the greatest hazard in life is to not live it to the full. Cancer brings a clarity to life and shows what is important in life and what's fluff.

Try to stay mindful of the pleasures of life happening around you. Once you enter a dark mindset, it can be hard to get out of it. But most of us have that one message of hope and inspiration that somehow manages to help bring some perspective and optimism to a situation. When you're dealing with cancer, a daily dose of inspiration may make a big difference in your outlook on life. Find that inspiration in your loved ones, your hobby, the gardens, flowers, nature—whatever brings you joy and more importantly fulfillment

# Fatigue & Anemia

Fatigue is the feeling of constant and excessive tiredness. Unlike typical tiredness, fatigue doesn't get better when you stop to rest. It's a common problem for people with cancer, and for those getting cancer treatment. If you're feeling tired or lack energy, talk to your cancer care team.

Fatigue can have many causes, including your cancer treatments, not eating enough, lack of sleep, depression, low blood counts, and some medicines. When the cause of the fatigue is medical, your doctor may be able to treat the cause to help you feel better.

Along with treatment, there are many nutrition steps you can take and other things you can try to help you cope with fatigue.

Anemia (from chemotherapy and/or your cancer) is a common cause.

Why it happens: Red blood cells carry oxygen throughout your body. Anemia is when you have too few red blood cells to carry the oxygen your body needs. Your heart works harder when your body does not get enough oxygen. This can make it feel like your heart is pounding or beating very fast. Anemia can also make you feel short of breath, weak, dizzy, faint, or very tired.

Some types of chemotherapy cause anemia because they make it harder for bone marrow to produce new red blood cells.

What your NMHOS team may do: Your cancer team may use red cell growth factors or blood transfusions. They may also choose to reduce your chemotherapy dose. Your blood will be checked to see if you are iron deficient, and if so, you will be given an oral or IV iron supplementation.

Get plenty of rest. Try to sleep at least 8 hours each night. You might also want to take 1 to 2 short naps (1 hour or less) during the day. Remember a longer nap may make it more difficult to sleep at night.

Limit your activities. This means doing only the activities that are most important to you. For example, you might go to work, but not clean the house. Or you might order take-out food, instead of cooking dinner.

Accept help. When your family or friends offer to help, let them. They can help care for your children, pick up groceries, run errands, drive you to doctor's visits, or do other chores you feel too tired to do.

Eat a well-balanced diet. Choose a diet that contains all the calories and protein your body needs. Calories will help keep your weight up, and extra protein can help repair tissues that have been harmed by cancer treatment. Talk to your doctor, nurse, or Artesia General Hospital dietitian about the diet that is right for you.

Stand up slowly. You may feel dizzy if you stand up too fast. When you get up from lying down, sit for a minute before you stand.

#### What else to do

- Try to prioritize your activities. Do the most important ones when you have the most energy.
- Take short walks or get regular exercise, if you can. More and more research tells us that being moderately active can help decrease cancer-related fatigue.
- Drink plenty of fluids. Dehydration can make fatigue worse. Be sure to get at least 8 cups of fluid each day. If you are losing weight, be sure to include some fluids that have calories, like juices or milk
- Try easier or shorter versions of your usual activities. Don't push yourself to do more than you can manage.
- Stress can make fatigue worse. Ask your cancer care team about stress management.

## When should I call my cancer care team?

If your level of fatigue changes, or you are not able to do your usual activities.

If you feel dizzy or like you are going to faint.

If you feel short of breath with minimal activity or at rest.

If it feels like your heart is pounding or beating very fast.

# Loss of Appetite

Chemotherapy can cause appetite changes. You may lose your appetite because of nausea (feeling sick to your stomach), mouth and throat problems that make it painful to eat, or drugs that cause you to lose your taste for food. Appetite changes can also come from feeling depressed or tired. This problem may last for a day, a few weeks, or even months.

It is important to eat well, even when you have no appetite. This means eating and drinking foods that have plenty of protein, vitamins, and calories. Eating well helps your body fight infection and repair tissues that are damaged by chemotherapy. Not eating well can lead to weight loss, weakness, and fatigue.

Some cancer treatments cause weight gain or an increase in your appetite. Be sure to ask your doctor, nurse, or dietitian what types of appetite changes you might expect and how to manage them.

# What your doctor may do:

Your team at NMHOS may discuss options such as appetite stimulants, medical marijuana or steroid use over a short period of time. However, these will be preceded by other interventions that we encourage you to do at home.

# Ways to manage

Eat five to six small meals or snacks each day, rather than three big meals. Many people find it easier to eat smaller amounts, more often. Choose foods and drinks that are high in calories and protein.

Set a daily schedule for eating your meals and snacks. Eat when it is time to eat, rather than when you feel hungry. You may not feel hungry while you are on chemotherapy, but you still need to eat.

Drink milkshakes, smoothies, juice, or soup if you do not feel like eating solid foods. Liquids like these can help provide the protein, vitamins, and calories your body needs.

Use plastic forks and spoons. Some types of chemotherapy give you a metal taste in your mouth. Eating with plastic can help decrease the metal taste. Cooking in glass pots and pans can also help.

Increase your appetite by doing something active. For instance, you might have more of an appetite if you take a short walk before lunch. Also, be careful not to lessen your appetite by drinking too much liquid before or during meals.

Change your routine. Eat in a different place, such as the dining room rather than the kitchen. Or, eat with other people instead of eating alone. If you eat alone, you may want to listen to the radio or watch TV. You may also want to vary your diet by trying new foods and recipes.

Talk with your doctor, nurse, or dietitian. He or she may want you to take extra vitamins or nutrition supplements (such as high protein drinks). If you cannot eat for a long time and are losing weight, you may need to take drugs that increase your appetite or receive nutrition through an IV or feeding tube.

# Nausea & Vomiting

# What they are and why they occur

Some types of chemotherapy can cause nausea, vomiting, or both. Nausea is when you feel sick to your stomach, like you are going to throw up. Vomiting is when you throw up. You may also have dry heaves, which is when your body tries to vomit even though your stomach is empty.

A person can have nausea with or without vomiting. If it's caused by chemo, nausea can happen on the day you get your treatment and/or can last for a few days – depending on what drugs you get. If you're getting radiation therapy to the belly, chest, brain, or pelvis, nausea can start shortly after treatment and last for several hours. Nausea and vomiting can have other causes, too. We call this early or delayed nausea depending on when it happens.

Nausea and vomiting can occur while you are getting chemotherapy, right after, or many hours or days later. You will most likely feel better on the days you do not get chemotherapy.

New drugs can help prevent nausea and vomiting. These are called antiemetic or anti-nausea drugs. You may need to take these drugs 1 hour before each chemotherapy treatment and for a few days after. How long you take them after chemotherapy will depend on the type of chemotherapy you are getting and how you react to it. If one anti-nausea drug does not work well for you, your doctor can prescribe a different one. You may need to take more than one type of drug to help with nausea. Acupuncture may also help. Talk with your doctor or nurse about treatments to control nausea and vomiting caused by chemotherapy.

# Ways to Manage or Prevent Nausea

Be sure to tell your cancer care team if you have nausea or are vomiting because there are medicines that can help.

Chemotherapy and certain chemicals released by tumors or even some opioid pain medications can. Trigger the CTZ (Chemotherapy Trigger zone) in the brain that can stimulate nausea and or vomiting. Constipation can also lead to nausea.

What your cancer team may do: Your team may prescribe anti-nausea medications like ondansetron, olanzapine. They may also add or increase anti-nausea medications to take with your IV chemotherapy as pre-medications. Brief use may help. Your team should also tell you how likely your regimen may be to cause mild, moderate or severe nausea. Preventive medications given may depend on the predicted intensity. The goal is minimum to no nausea and no vomiting. We have very effective medications to prevent nausea and vomiting and many tools available to use.

One way to prevent vomiting is to prevent nausea. Try having bland, easy-to-digest foods and drinks that do not upset your stomach. These include plain crackers, toast, and gelatin.

Plan when it's best for you to eat and drink. Some people feel better when they eat a light meal or snack before chemotherapy. Others feel better when they have chemotherapy on an empty stomach (nothing

to eat or drink for 2 to 3 hours before treatment). After treatment, wait at least 1 hour before you eat or drink.

Eat small meals and snacks. Instead of three large meals each day, many people find it easier to eat if they have five or six small meals and snacks. It also helps not to drink a lot before or during meals and avoid lying down right after you eat.

Eat and drink items that are not too hot nor too cold. Give hot foods and drinks time to cool down or make them colder by adding ice. You can warm up cold foods by taking them out of the refrigerator 1 hour before you eat or warming them slightly in a microwave. Drink cola or ginger ale that is warm and has lost its fizz.

Avoid strong smells. Try to avoid foods and drinks with strong smells, such as coffee, fish, onions, garlic, and foods that are cooking.

Small bites of popsicles may help manage nausea, and will help keep you hydrated. You may also find ice chips helpful.

Sugar-free mints or tart candies may help if you have a bad taste in your mouth. However, tart candies may not be appropriate if you have mouth or throat sores.

## Relax before treatment

You may feel less nausea if you relax before each chemotherapy treatment. Meditate, do deep breathing exercises, or imagine scenes or experiences that make you feel peaceful. You can also do quiet hobbies such as reading, listening to music, or knitting. For relaxation exercises, visit Learning to Relax on the National Cancer Institute's web site at: <a href="https://www.cancer.gov/about-cancer/coping/feelings/relaxation">www.cancer.gov/about-cancer/coping/feelings/relaxation</a>.

When you feel like vomiting, breathe deeply and slowly or get fresh air. You might also distract yourself by chatting with friends or family, listening to music, or watching a movie or TV shows.

Talk with your doctor or nurse. Your doctor can give you drugs to help prevent nausea during and after chemotherapy. Be sure to take these drugs as ordered and let your doctor or nurse know if they do not work. You might also ask your doctor or nurse about acupuncture, which can help relieve nausea and vomiting caused by cancer treatment.

Tell your doctor or nurse if you vomit for more than one day or right after you drink.

If you aren't able to keep fluids down, contact your doctor immediately.

- Eat a light meal before your treatment (e.g. soup and crackers, or toast), and drink as much fluid as possible. Eat small snacks frequently rather than big meals.
- Sip fluids throughout the day, rather than trying to drink a lot at once. Ice chips, popsicles, or fruit ices can also help to increase your fluid intake.
- If your stomach is upset, try drinking fizzy drinks such as soda water or dry ginger ale. If you wake up feeling sick, eat a cracker or a slice of toast rather than skipping food altogether or forcing yourself to have a full meal.

- Breathe deeply and gently through your mouth if you feel like you're going to vomit.
- Avoid strong odors and cooking smells.
- Eat and drink slowly. Chew your food well to make it easier to digest.
- Prepare meals between treatments and freeze them for the days you don't feel like cooking.
- Eat what you feel like eating, when you feel like it. For example, have cereal at dinner time and a main meal at lunch.
- If the taste of certain types of food has changed, don't force yourself to eat them. Your sense of taste should return to normal after treatment ends, but it may take some time.
- Ask your treatment team about taking a stool softener if the drugs make you constipated.

## What else to do (some tips from patients)

- Eat 6 to 8 snacks or small meals a day, instead of 3 large meals.
- Eat dry foods, like crackers, toast, dry cereals, or bread sticks, when you wake up and every few hours during the day.
- Eat foods that don't have strong odors.
- Eat cool foods instead of hot or spicy foods.
- Avoid foods that are overly sweet, greasy, fried, or spicy.
- If you need to rest, sit up or recline with your head raised for at least an hour after eating.
- Hard candy, like peppermints or lemon drops, may help if there's a bad taste in your mouth.

# Bleeding

# What it is and why it occurs

Platelets are cells that make your blood clot when you bleed. Chemotherapy can lower the number of platelets because it affects your bone marrow's ability to make them. A low platelet count is called thrombocytopenia. This condition may cause bruises even when you have not been hit or have not bumped into anything, bleeding from your nose or in your mouth, or a rash of tiny, red dots.

# Ways to manage:

- Brush your teeth with a very soft toothbrush.
- Soften the bristles of your toothbrush by running hot water over them before you brush.
- Use a water flosser to clean your gums and between your teeth.
- Blow your nose gently.
- Be careful when using scissors, knives, or other sharp objects.

- Use an electric shaver instead of a razor.
- Apply gentle but firm pressure to any cuts you get until the bleeding stops.
- Wear shoes all the time, even inside the house or hospital.

#### Do not:

- Use dental floss or toothpicks.
- Play sports or do other activities during which you could get hurt.
- Use tampons, enemas, suppositories, or rectal thermometers.
- Wear clothes with tight collars, wrists, or waistbands.

#### Check with your doctor or nurse before:

- Drinking beer, wine, or other types of alcohol.
- Having sex.
- Taking vitamins, herbs, minerals, dietary supplements, aspirin, or other over-the-counter medicines. Some of these products can change how chemotherapy works.

Let your doctor know if you are constipated. He or she may prescribe a stool softener to prevent straining and rectal bleeding when you go to the bathroom.

Your doctor or nurse will frequently check your blood count.

You may need medication, a platelet transfusion, or a delay in your chemotherapy treatment if your platelet count is too low.

# Call your doctor or nurse if you have any of these symptoms

- Bruises, especially if you did not bump into anything
- Small, red spots on your skin
- Red- or pink-colored urine
- Black or bloody bowel movements
- Bleeding from your gums or nose
- Heavy bleeding during your menstrual period or for a prolonged period
- Vaginal bleeding not caused by your period
- Headaches or changes in your vision
- A warm or hot feeling in your arm or leg
- Feeling very sleepy or confused

# Constipation

Constipation is when bowel movements become less frequent and stools are hard, dry, and difficult to pass. You may have painful bowel movements and feel bloated or nauseous. You may belch, pass a lot of gas, and have stomach cramps or pressure in the rectum.

Drugs such as chemotherapy and pain medicine, especially narcotics, can cause constipation. It can also happen when people are not active and spend a lot of time sitting or lying down. Constipation can also be due to eating foods that are low in fiber or not drinking enough fluids.

## Ways to manage

Keep a record of your bowel movements. Show this record to your doctor or nurse and talk about what is normal for you. This makes it easier to figure out whether you have constipation.

Drink at least eight cups of water or other fluids each day. Try water, prune juice, warm juices, teas, and hot lemonade. (A hot beverage may help to stimulate a bowel movement).

Be active every day. You can be active by walking, riding a bike, or doing yoga. If you cannot walk, ask about exercises that you can do in a chair or bed. Talk with your doctor or nurse about ways you can be more active.

Check with your doctor or nurse before using fiber supplements, laxatives, stool softeners, or enemas.

Ask your doctor, nurse, or dietitian about foods that are high in fiber. Eating high-fiber foods and drinking lots of fluids can help soften your stools. Good sources of fiber include whole-grain breads and cereals, dried beans and peas, raw vegetables, fresh and dried fruit, nuts, seeds, and popcorn.

Let your doctor or nurse know if you have not had a bowel movement in two days. Your doctor may suggest a fiber supplement, laxative, stool softener, or enema. Do not use these treatments without first checking with your doctor or nurse.

Pain medicines, changes in your eating habits, and being less active can cause your bowels to move less often and stools to become harder to pass (constipation). If you're constipated, try eating high-fiber foods. Also drink extra fluids during the day, eat at regular times, and try to increase your physical activity, if possible.

#### When to call your cancer care team

If you haven't had passed gas or had a bowel movement for 2-3 days and/or your bowel is distended or stiff and painful. It could be a sign of a bowel obstruction.

# Diarrhea

What it is and why it occurs Diarrhea is frequent bowel movements that may be soft, loose, or watery. Chemotherapy can cause diarrhea because it harms healthy cells that line your large and small intestines. It may also speed up your bowels. Diarrhea can also be caused by infections or drugs used to treat constipation.

### Ways to manage

Eat five or six small meals and snacks each day instead of three large meals. Many people find it easier to eat smaller amounts more often.

Ask your doctor or nurse about foods that are high in salts such as sodium and potassium. Your body can lose these salts when you have diarrhea, and it is important to replace them. Foods that are high in sodium or potassium include bananas, oranges, peach and apricot nectar, and boiled or mashed potatoes. Consider replacing lost fluid with Pedialyte®

Drink eight to twelve cups of clear liquids each day. Examples include water, clear broth, ginger ale, or sports drinks such as Gatorade® or Propel®. Drink slowly and choose drinks that are at room temperature. Let carbonated drinks lose their fizz before you drink them. Add extra water if drinks make you thirsty or sick to your stomach.

Eat low-fiber foods. Foods that are high in fiber can make diarrhea worse. Low-fiber foods include bananas, white rice, white toast, and plain or vanilla yogurt.

Let your doctor or nurse know if your diarrhea lasts for more than 24 hours or if you have pain and cramping along with diarrhea. Your doctor may prescribe a medicine to control the diarrhea. You may also need IV fluids to replace the water and nutrients you lost. Do not take any medicine for diarrhea without first asking your doctor or nurse.

Be gentle when you wipe yourself after a bowel movement. Instead of toilet paper, use a baby wipe or squirt of water from a spray bottle to clean yourself after bowel movements. Let your doctor or nurse know if your rectal area is sore or bleeds or if you have hemorrhoids.

Ask your doctor if you should try a clear liquid diet. This can give your bowels time to rest. Most people stay on this type of diet for five days or less.

#### Avoid:

- Drinks that are very hot or very cold
- Beer, wine, and other types of alcohol
- Milk or milk products, such as ice cream, milkshakes, sour cream, and cheese
- Spicy foods, such as hot sauce, salsa, chili, and curry dishes
- Greasy and fried foods, such as French fries and hamburgers
- Foods or drinks with caffeine, such as regular coffee, black tea, cola, and chocolate

- Foods or drinks that cause gas, such as cooked dried beans, cabbage, broccoli, and soy milk and other soy products
- Foods that are high in fiber, such as cooked dried beans, raw fruits and vegetables, nuts, and whole-wheat breads and cereals.

### When to call your cancer care team

Call your cancer care team if diarrhea continues or increases, or if your stools have an unusual odor or color. Being on Immunotherapy may cause diarrhea that is usually treated with steroids. Your Urgent care or ER physician should be informed if you are on immunotherapy.

### Hair Loss

# What it is and why it occurs

Hair loss (also called alopecia) is when some or all of your hair falls out. This can happen anywhere on your body: your head, face, arms, legs, underarms, or the pubic area between your legs. Many people are upset by the loss of their hair and find it the most difficult part of chemotherapy.

Not all chemotherapy causes hair loss. In fact, immunotherapy and biological therapies don't cause hair loss. Some types of chemotherapy however damage the cells that cause hair growth.

Hair loss often starts two to three weeks after chemotherapy begins. Your scalp may hurt at first. Then you may lose your hair, either a little at a time or in clumps. It takes about one week for all your hair to fall out. Almost always, your hair will grow back two to three months after chemotherapy is over. You may notice that your hair starts growing back even while you are getting chemotherapy.

Your hair will be very fine when it starts growing back. Also, your new hair may not look or feel the same as it did before. For instance, your hair may be thin instead of thick, curly instead of straight, and darker or lighter in color.

When hair loss does occur, it usually starts 2–3 weeks after the first treatment and grows back when chemotherapy is completed. Before, and while your hair is falling out, your scalp may feel hot, itchy, tender or tingly. Some people find that the skin on their head is extra sensitive, and they may develop pimples on their scalp.

It usually takes 4–12 months to grow back a full head of hair. When your hair first grows back, it may be a different color than before. It could also be curly, even if you have always had straight hair. In time hair usually returns to its normal condition.

Many people find losing their hair very difficult. You may feel that your hair is part of your overall image and its loss can make you feel physically unattractive, vulnerable or sad. It's natural to feel this way. Talking to your medical team may be helpful

# Ways to manage before hair loss

Talk with your doctor or nurse. He or she will know if you are likely to have hair loss.

You might feel more in control of hair loss if you cut your hair or shave your head yourself first. This often makes hair loss easier to manage. If you shave your head, use an electric shaver instead of a razor.

Choose your wig before you start chemotherapy. This way, you can match the wig to the color and style of your hair. You might also take it to your hairdresser who can style the wig to look like your own hair. Make sure to choose a wig that feels comfortable and does not hurt your scalp.

Ask if your insurance company will pay for a wig. If it will not, you may be able to deduct the cost of your wig as a medical expense on your income tax. Some groups also have free "wig banks." Your doctor, nurse, or social worker will know if there is a wig bank near you.

Be gentle when you wash your hair. Use a mild shampoo, such as a baby shampoo. Dry your hair by patting (not rubbing) it with a soft towel.

## Do not use items that can hurt your scalp

#### These include:

- Straightening or curling irons
- Brush rollers or curlers
- Electric hair dryers
- Hair bands and clips
- Hairsprays
- Hair dyes
- Products to perm or relax your hair

### After hair loss

Protect your scalp. Your scalp may hurt during and after hair loss. Protect it by wearing a hat, turban, or scarf when you are outside. Try to avoid places that are very hot or very cold. This includes tanning beds and outside in the sun or cold air. And always apply sunscreen or sunblock to protect your scalp.

Stay warm. You may feel colder once you lose your hair. Wear a hat, turban, scarf, or wig to help you stay warm.

Sleep on a satin pillowcase. Satin creates less friction than cotton when you sleep on it. Therefore, you may find satin pillowcases more comfortable.

**Talk about your feelings**. Many people feel angry, depressed, or embarrassed about hair loss. If you are very worried or upset, you might want to talk about these feelings with a doctor, nurse, family member, close friend, or someone who has had hair loss caused by cancer treatment.

#### Other hair tips

- Keep your hair and scalp very clean.
- Use a mild shampoo like baby shampoo.
- Comb or brush your hair gently using a large comb or hairbrush with soft bristles.

- Cut your hair, especially if long, before it falls out. This can be less upsetting.
- Wear a light cotton turban or beanie to bed if you are cold at night, or to collect hair.
- Use a cotton, polyester or satin pillowcase, as nylon can irritate your scalp. If you prefer to leave your head bare, protect it against sunburn and the cold.
- Limit the use of hair dryers, rollers and harsh products.
- Talk to your hairdresser about making your hair look as good as possible even if it is thin or patchy. After recovery, if you want to dye your hair, you can use vegetable-based or low-chemical dyes. Test a small area of hair for a reaction before coloring your whole head.
- If your eyelashes fall out, wear glasses or sunglasses to protect your eyes from the dust and sun while outside.
- Tell your nurse or doctor if the skin on your scalp is very sensitive, or if you have a lot of discomfort and itchiness.
- Wear a wig, toupee, hat, scarf or turban. Do whatever feels the most comfortable and gives you the most confidence.

Ways to learn more American Cancer Society Offers a variety of services to people with cancer and their families, including referrals to low-cost wig banks. Call: 1-800-ACS-2345 (1-800-227-2345) TTY: 1-866-228-4327 Visit: <a href="https://www.cancer.org">www.cancer.org</a>

# Risk of Infection "Neutropenic fevers"

### What it is and why it occurs

Some types of chemotherapy make it harder for your bone marrow to produce new white blood cells. White blood cells help your body fight infection. Since chemotherapy decreases the number of your white blood cells, it is important to avoid infections. The risk of these infections is usually higher in those receiving chemotherapy for blood cancers.

Some chemotherapy drugs affect the bone marrow, which is the soft and spongy material inside the bones. The bone marrow makes three types of blood cells:

- 1. red blood cells carry oxygen throughout the body
- 2. white blood cells fight infection
- 3. platelets help blood to clot and prevent bruising.

There are many types of white blood cells. One type is called a neutrophil. When your neutrophil count is low, it is called neutropenia. Your doctor or nurse will do blood tests to find out whether or not you have neutropenia.

It is important to watch for signs of infection when you have neutropenia. Check for fever at least once a day, or as often as your doctor or nurse tells you to. You may find it best to use a digital thermometer. Many doctors will want you to call if you have a fever of 100.5°F or higher, but this can vary. Ask your doctor or nurse when you should call to report a high fever.

### Ways to manage

Your doctor or nurse will check your white blood cell count throughout your treatment. If chemotherapy is likely to make your white blood cell count very low, you may get medicine to raise your white blood cell count and lower your risk of infection.

Wash your hands often with soap and water. Be sure to wash your hands before cooking and eating, and after you use the bathroom, blow your nose, cough, sneeze, or touch animals. Carry hand sanitizer for times when you are not near soap and water.

Use sanitizing wipes to clean surfaces and items that you touch. This includes public telephones, ATM machines, doorknobs, and other common items.

Be gentle and thorough when you wipe yourself after a bowel movement. Instead of toilet paper, use a baby wipe or squirt of water from a spray bottle to clean yourself. Let your doctor or nurse know if your rectal area is sore or bleeds or if you have hemorrhoids.

Stay away from people who are sick. This includes people with colds, flu, measles, or chicken pox. You also need to stay away from children who just had a "live virus" vaccine for chicken pox or polio. Call your doctor, nurse, or local health department if you have any questions.

Stay away from crowds. Try not to be around a lot of people. For instance, plan to go shopping or to the movies when the stores and theaters are less crowded.

Be careful not to cut or nick yourself. Do not cut or tear your nail cuticles. Use an electric shaver instead of a razor. And be extra careful when using scissors, needles, or knives.

Watch for signs of infection around your catheter. Signs to look for include drainage, redness, swelling, or soreness. Tell your doctor or nurse about any changes you notice near your catheter.

Maintain good mouth care. Brush your teeth after meals and before you go to bed. Use a very soft toothbrush. You can make the bristles even softer by running hot water over them just before you brush. Use a mouth rinse that does not contain alcohol. Check with your doctor or nurse before going to the dentist. (For more about taking care of your mouth.

Take good care of your skin. Do not squeeze or scratch pimples. Use lotion to soften and heal dry, cracked skin. Dry yourself after a bath or shower by gently patting your skin. Be careful not to rub your skin. For more information about taking care of your skin.

Clean cuts right away. Use warm water, soap, and an antiseptic to clean your cuts. Clean your cut like this every day until your cut has a scab over it.

Be careful around animals. Do not clean your cat's litter box, pick up dog waste, or clean bird cages or fish tanks. Be sure to wash your hands after touching pets and other animals.

Do not get a flu shot or other type of vaccine without first asking your doctor or nurse. Some vaccines contain a live virus, which you should not be exposed to.

Keep hot foods hot and cold foods cold. Do not leave leftovers sitting out. Put them in the refrigerator as soon as you are done eating.

Wash raw vegetables and fruits well before eating them. Avoid anything that cannot be washed well, or has many bumps, like raspberries. Do not eat raw or undercooked fish, seafood, meat, chicken, or eggs. These foods may have bacteria that can cause infection. Do not eat or drink items that are past the freshness date. Do not eat foods that have moldy spots, even if you cut them out.

Do not take drugs that reduce fever without first talking with your doctor or nurse.

#### Call your doctor right away if you think you have an infection.

If you think you have an infection, it's important to let your doctor know as soon as possible, even if it's the weekend or in the middle of the night. Be sure you know how to reach your doctor after office hours and on weekends. Also call right away if you have chills or sweats or a fever of 100.5°F or higher.

Do not take aspirin, acetaminophen (such as Tylenol®), ibuprofen products, or any other drugs that reduce fever without first talking with your doctor or nurse.

Besides fever, other signs of infection include:

- Redness
- Swelling
- Rash
- Chills
- Cough
- Earache
- Headache
- Stiff neck
- Bloody or cloudy urine
- Painful or frequent need to urinate
- Sinus pain and pressure

# Infertility

## What it is and why it occurs

Some types of chemotherapy can cause infertility. For women, this means that you may not be able to become pregnant, as chemotherapy may cause damage to the ovaries. This damage can lower the number of healthy eggs in the ovaries, and can lower the hormones produced by them. The drop in hormones can lead to early menopause. Early menopause and fewer healthy eggs can cause infertility.

For men, this means you may not be able to father a child. Chemotherapy can cause damage to sperm cells, which grow and divide quickly. Infertility may occur because chemotherapy can lower the number of sperm, make sperm less able to move, or cause other types of damage. Before treatment starts, tell your doctor or nurse if you want to have children in the future.

#### Ways to manage for women

Before you start chemotherapy, let your doctor or nurse know if you might want to get pregnant in the future. He or she may talk with you about ways to preserve your eggs to use after treatment ends or refer you to a fertility specialist.

It is very important that you do not get pregnant while receiving chemotherapy. These drugs can hurt the fetus, especially in the first three months of pregnancy. If you have not yet gone through menopause, talk with your doctor or nurse about birth control and ways to prevent pregnancy. If you still have menstrual periods, your doctor or nurse may ask you to have a pregnancy test before you start chemotherapy. If you are pregnant, your doctor or nurse will talk with you about other treatment options.

### Ways to manage for men

Before you start chemotherapy, let your doctor or nurse know if you might want to father children in the future. He or she may talk with you about ways to preserve your sperm to use in the future or refer you to a fertility specialist.

It is very important that your spouse or partner not get pregnant during your course of your chemotherapy. Chemotherapy may damage sperm and cause birth defects. Use of contraceptives such as condoms are highly recommended to make sure pregnancy does not occur.

#### Key points

- For some women, periods become irregular during chemotherapy but return to normal after treatment. For others, chemotherapy may cause periods to stop completely (menopause).
- After menopause, women can't have children. Signs of menopause include hot flushes, sweating especially at night and dry skin.
- Menopause particularly if before age 40 may, in the long term, cause bones to become weaker and break more easily. This is called osteoporosis.
- Talk to your doctor about ways to manage menopausal symptoms.
- Chemotherapy drugs may lower the number of sperm produced and reduce their ability to move. This can sometimes cause infertility, which may be temporary or permanent.
- The ability to get and keep an erection may also be affected but this is usually temporary. If the problem is ongoing, seek medical advice.

Ways to learn more American Cancer Society Offers a variety of services to people with cancer and their families. Call: 1-800-ACS-2345 (1-800-227-2345) Visit: <a href="http://www.cancer.org">http://www.cancer.org</a>

Livestrong fertility program; a LIVESTRONG fertility initiative dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility. Call: 1-855-844-7777 Visit: <a href="https://www.livestrong.org/we-can-help/livestrong-fertility">https://www.livestrong.org/we-can-help/livestrong-fertility</a>

# Mouth and Throat Changes

# What they are and why they occur

Some types of chemotherapy harm fast-growing cells, such as those that line your mouth, throat, and lips. This can affect your teeth, gums, the lining of your mouth, and the glands that make saliva. Most mouth problems go away a few days after chemotherapy is over.

## Mouth and throat problems may include:

- Dry mouth
- Changes in taste and smell, such as when food tastes like metal or chalk, has no taste, or does not taste or smell like it used to
- Infections of your gums, teeth, or tongue
- Increased sensitivity to hot or cold foods
- Mouth sores
- Trouble eating when your mouth gets very sore

### Ways to manage

Visit a dentist at least two weeks before starting chemotherapy. It is important that your mouth is as healthy as possible, which means having all your dental work done before chemotherapy starts. If you cannot go to the dentist before chemotherapy starts, ask your doctor or nurse when it is safe to go. Be sure to tell your dentist that you have cancer and about your treatment plan.

Check your mouth and tongue every day. By checking your mouth, you can see or feel problems (such as mouth sores, white spots, or infections) as soon as they start. Inform your doctor or nurse right away if you see any of these problems.

Keep your mouth moist. You can keep your mouth moist by sipping water throughout the day, sucking on ice chips or sugar-free hard candy, or chewing sugar-free gum. Ask your doctor or nurse about saliva substitutes if your mouth is always dry.

#### Clean your mouth, teeth, gums, and tongue.

- Brush your teeth, gums, and tongue after each meal and at bedtime.
- Use an extra-soft toothbrush. You can make the bristles even softer by rinsing your toothbrush in hot water before you brush.
- If brushing is painful, try cleaning your teeth with cotton swabs or Toothettes®, which are shaped sponges on a stick.
- Use a fluoride toothpaste or special fluoride gel that your dentist prescribes.
- Do not use mouthwash that has alcohol. Instead, rinse your mouth three to four times a day with a solution of baking soda, salt, and warm water followed by a plain water rinse. There are

- many recipes for this solution, but an example is 1/4 teaspoon baking soda, 1/8 teaspoon salt, and 1 cup of warm water. Gargle with the mixture to relieve a sore throat, but don't swallow it.
- Gently floss your teeth every day. If your gums bleed or hurt, avoid those areas but floss your other teeth. Ask your doctor or nurse about flossing if your platelet count is low.
- If you wear dentures, keep them clean and make sure they fit well. Also, limit the length of time that you wear them. Be careful what you eat when your mouth is sore.

#### What to do for mouth sores

- Drink 8 to 10 cups of liquid a day, and take a water bottle wherever you go. (Drinking lots of fluids helps thin mucus.), eat soft, bland foods like creamed soup, cooked cereal, macaroni and cheese, yogurt, and pudding.
- Puree or liquefy foods in a blender to make them easier to swallow.
- Eat foods cold or lukewarm, rather than hot, to reduce mouth irritation.
- Drink through a straw to bypass mouth sores.
- Avoid rough, dry, or coarse foods.
- Eat high-protein, high-calorie foods to speed healing.
- Avoid alcohol, carbonated beverages, and tobacco.
- Avoid commercial mouthwashes, alcoholic and acidic drinks, and tobacco
- Your doctor can prescribe a "swish and swallow" mouthwash with a numbing agent if needed. Ask about this if you think it will help.
- Choose foods that are moist, soft, and easy to chew or swallow. These include cooked cereals, mashed potatoes, and scrambled eggs.
- Use a blender to puree cooked foods so that they are easier to eat. To help avoid infection, be sure to wash all blender parts before and after using them. If possible, it is best to wash them in a dishwasher.
- Take small bites of food, chew slowly, and sip liquids while you eat.
- Soften food with gravy, sauces, broth, yogurt, or other liquids.
- Eat foods that are cool or at room temperature. You may find that warm and hot foods hurt your mouth or throat.
- Try ice chips or popsicles. These can relieve mouth pain.
- Ask your dietitian for ideas of foods that are easy to eat.

#### What else to avoid

Avoid things that can hurt, scrape, or burn your mouth, such as:

- Sharp or crunchy foods, such as crackers and potato or corn chips
- Spicy foods, such as hot sauce, curry dishes, salsa, and chili
- Citrus fruits or juices such as orange, lemon, and grapefruit
- Food and drinks that have a lot of sugar, such as candy or soda
- Beer, wine, and other types of alcohol
- Toothpicks or other sharp objects
- Tobacco products, including cigarettes, pipes, cigars, and chewing tobacco Do not use tobacco or drink alcohol if your mouth is sore.

Ways to learn more National Oral Health Information Clearinghouse A service of the National Institute of Dental and Craniofacial Research that provides oral health information for special care patients. Call: 1-866-232-4528 Visit: www.nidcr.nih.gov E-mail: nidcrinfo@mail.nih.gov

Smokefree.gov Provides resources including information on quit lines, a step-by-step cessation guide, and publications to help you or someone you care about quit smoking. Call: 1-877-44U-QUIT (1-877-448-7848)

# Swallowing problems

Cancer and its treatments can sometimes cause trouble with swallowing. If you're having problems swallowing, try eating soft or liquid foods. You may be able to swallow thick fluids more easily than thin liquids. If you're unable to eat enough regular foods to meet your nutritional needs, drink high-calorie and high-protein liquids.

Your doctor may refer you to a speech therapist. This is an expert health professional who can teach you how to swallow better and how to decrease coughing and choking when you eat and drink.

#### What to do

- Follow your speech therapist's instructions for any special eating techniques.
- Call your cancer care team right away if you cough or choke while eating, especially if you have developed a fever.
- Eat small, frequent meals.
- Use canned liquid nutritional supplements if you're unable to eat enough food to meet your needs.

#### Try these thickening products:

Gelatin (animal based), Pectin (plant based): Use to help soften cakes, cookies, crackers, sandwiches, pureed fruits, and other cold food.

Mix 1 tablespoon unflavored gelatin in 2 cups hot liquid until dissolved; pour over food. Allow food to sit until saturated. Tapioca, flour, and cornstarch: Use to thicken liquids. Note that these must be cooked before using.

Commercial thickeners: Follow label instructions and use to adjust a liquid's thickness. Pureed vegetables and instant potatoes: Use in soups. Note that these change the food's flavor. Baby rice cereal: Use to make a very thick product.

# If thin liquids are recommended for you, try these:

Coffee, tea, soft drinks, liquid nutritional supplements, Italian ice, sherbet, broth, and thin cream-based soups.

If your team has recommended thick liquids, try any of these: buttermilk, eggnog, milk shakes, yogurt shakes, and ice cream.

# Taste and Smell Changes

Cancer and its treatments can change your senses of taste and smell. These changes can affect your appetite and are often described as a bitter or metallic taste. If you're having these problems, try foods, marinades, spices, drinks, and ways of preparing foods that are different from those you usually use. Also, keep your mouth clean by rinsing and brushing, which may help foods taste better.

#### What to do

- Try using plastic flatware and glass cups and plates.
- Try sugar-free lemon drops, gum, or mints.
- Try fresh or frozen fruits and vegetables instead of canned.
- Season foods with tart flavors like lemon wedges, lemonade, citrus fruits, vinegar, and pickled foods. (If you have a sore mouth or throat, do not do this.)
- Rinse your mouth with a baking soda, salt, and water mouthwash before eating to help foods taste better. (Mix 1 teaspoon salt and 1 teaspoon baking soda in 1 quart water. Shake well before swishing and spitting.)
- If red meats taste strange, try other protein-rich foods like chicken, fish, eggs, or cheese.
- Blend fresh fruits into shakes, ice cream, or yogurt.
- To reduce smells, cover beverages and drink through a straw; choose foods that don't need to be cooked; and avoid eating in rooms that are stuffy or too warm.

# Weight Gain

Some people find they don't lose weight during treatment. They may even gain weight. This is particularly true for people with breast, prostate, or ovarian cancer who are taking certain medicines or getting hormone therapy or chemotherapy.

If you notice you're gaining weight, tell your cancer care team so you can find out what may be causing this change.

Here are some patient tips that can help:

#### What to do

- Ask your cancer care team for a referral to a registered dietitian at Artesia General Hospital to help you get your nutrition needs met without gaining weight.
- Try to walk daily if you can and if it's OK with your doctor. Talk with your cancer care team about referral to a physical therapist to help you safely increase activity levels.
- Limit food portion sizes, especially with high-calorie foods.

• Choose fish, poultry, or beans and peas instead of red meat. If you eat red meat, choose only lean cuts and eat smaller portions.

Choose whole-grain breads, pasta, and cereals (such as barley and oats) instead of breads, cereals, and pasta made from refined grains, and brown rice instead of white rice. • Limit your intake of refined carbohydrate foods, including pastries, candy, sugar-sweetened breakfast cereals, and other high-sugar foods.

# Nervous System Changes

Chemotherapy can cause damage to your nervous system. Many nervous system problems get better within a year of when you finish chemotherapy, but some may last the rest of your life.

Some chemotherapy drugs like Oxaliplatin, Vincristine, taxanes are notorious for causing neuropathy

# Symptoms may include:

- Tingling, burning, weakness, or numbness in your hands or feet
- Feeling colder than normal
- Pain when walking
- Weak, sore, tired, or achy muscles
- Being clumsy and losing your balance
- Trouble picking up objects or buttoning your clothes
- Shaking or trembling
- Hearing loss
- Stomach pain, such as constipation or heartburn
- Fatigue
- Confusion and memory problems
- Dizziness
- Depression

#### Ways to manage nervous system side effects

Be careful when handling knives, scissors, and other sharp or dangerous objects. Think about wearing gloves while gardening or cooking for extra protection.

Avoid falling. Walk slowly, hold onto handrails when using the stairs, and put no-slip bath mats in your bathtub or shower. Make sure there are no area rugs or cords to trip over. Always wear sneakers, tennis shoes, or other lace-up footwear with rubber soles. Steady yourself when you walk by using a cane or other device.

Be careful when using hot water. Use a thermometer to check the temperature in your bath or ask someone to check it for you. Wear gloves when washing dishes. Think about lowering the temperature on your hot water heater.

Rest when you need to. Ask for help taking care of household tasks and errands.

### When to talk to your doctor or nurse:

Let them know right away if you notice any nervous system changes, including memory problems and feelings of confusion or depression.

# Pain

### What it is and why it occurs

Some types of chemotherapy cause painful side effects, such as burning, numbness, and tingling or shooting pains in your hands and feet. They can also cause mouth sores, headaches, muscle pains, and stomach pains.

Pain can be caused by the cancer itself or by chemotherapy. Doctors and nurses have ways to decrease or relieve your pain.

Be sure to tell your doctor or nurse if you have pain.

### Ways to manage pain

Talk about your pain with a doctor, nurse, or pharmacist. Be specific and describe:

- Where you feel pain: Is it in one part of your body or all over?
- What the pain **feels like**: Is it sharp, dull, or throbbing? Does it come and go, or is it steady?
- **How strong** the pain is: Describe it on a scale of 0 to 10.
- How long the pain lasts: Does it last for a few minutes, an hour, or longer?
- What makes the pain **better or worse:** For instance, does an ice pack help? Or does the pain get worse if you move a certain way?

Which medicines do you take for pain? Do they help? How long do they last? How much do you take and how often?

Your physician usually titrates a 'step-up' plan to manage your pain, starting with non-narcotic NSAIDs and some additional medicines like gabapentin to control neuropathic pain. More severe pain sometimes needs narcotic medicines like Tramadol and stronger opioids like morphine or its derivatives. You may only receive small amounts of these medications, as opioids are very carefully managed. Short acting narcotics usually cover pain for 4-6 hrs.

If your team notices that you are requiring them more often they may suggest using twice a day long acting morphine (MS Contin, Oxycontin); which has 8 to 12 hr. pain control. Patches to control baseline pain for about 72 hours are also available, however your oncologist or palliative care team will determine whether these are safe for you. Medical marijuana may be added to help reduce your opioid requirements or to help reduce your pain symptoms.

It is very important that you have Narcan available as an antidote for opioid overdose. You and your caretakers should also be able to recognize the symptoms of an opioid emergency.

Patients being treated for cancer may have changes in their metabolism that place them at higher risk for overdose. These may include weight loss, dehydration and generalized loss of condition. These changes may cause a "regular" dose of pain medication to become an inadvertent overdose. Patients, families and close friends all need to learn the signs of a potential overdose.

### Signs and Symptoms of Opioid Overdose

When a person takes a higher dose of opioids than their body and brain are able to manage, they may experience an overdose. An opioid overdose can be life-threatening, so if you suspect you are experiencing an overdose you should seek professional, medical help immediately.

There are 3 key symptoms to look for, referred to as the "opioid overdose triad" 2:

- Pinpoint pupils
- Slowed or stopped breathing
- Unconsciousness/non-responsiveness

**Respiratory depression** is one of the most dangerous symptoms because it can lead to hypoxia or inadequate blood oxygenation, which can cause permanent brain damage or even death <sup>3</sup>. Another risk with opioid medications is a slowed or stopped heart rate. This can also be fatal <sup>4,5</sup>.

#### Additional symptoms to look for<sup>5</sup>:

- Limp body
- Pale face
- Clammy skin
- Purple or blue color to lips and fingernails
- Vomiting

If any of these symptoms present in an opioid user, seek emergency medical help immediately.

### Narcan for suspected opioid emergency

#### Indication and important safety information

NARCAN® (naloxone HCl) Nasal Spray is used for the treatment of an opioid emergency or a possible opioid overdose with signs of breathing problems and severe sleepiness or not being able to respond. NARCAN® Nasal Spray is to be given right away and does not take the place of emergency medical care. Get emergency medical help right away after giving the first dose of NARCAN® Nasal Spray, even if the person wakes up because symptoms may return. Repeat doses may be necessary. Do not use NARCAN® Nasal Spray if you are allergic to naloxone hydrochloride or any of the ingredients in NARCAN® Nasal Spray.

# What is the most important information I should know about NARCAN® Nasal Spray?

NARCAN® Nasal Spray is used to temporarily reverse the effects of opioid medicines. The medicine in NARCAN® Nasal Spray has no effect in people who are not taking opioid medicines.

Use NARCAN® Nasal Spray right away if you or your caregiver think signs or symptoms of an opioid emergency are present, even if you are not sure, because an opioid emergency can cause severe injury or death

Family members, caregivers, or other people who may have to use NARCAN® Nasal Spray in an opioid emergency should know where NARCAN® Nasal Spray is stored and how to give NARCAN® before an opioid emergency happens.

Get emergency medical help right away after giving the first dose of NARCAN® Nasal Spray.

Rescue breathing or CPR (cardiopulmonary resuscitation) may be given while waiting for emergency medical help.

The signs and symptoms of an opioid emergency can return after NARCAN® Nasal Spray is given. If this happens, give another dose after 2 to 3 minutes using a new NARCAN® Nasal Spray and watch the person closely until emergency help is received.

You may feel as if there is no chance you will need the Narcan that is prescribed with your first dose of narcotic pain medications. Please reconsider this and keep it on hand in the home, in case some child happens to get your medication, or you happen to suddenly have an unexpected event related to pain medications.

Remember to secure your narcotic medications within your home. You are responsible for these medications, and refills will not be done for medications that are lost, stolen, or taken in excess of the prescribed frequency. Be sure to keep them out of the hands of children, as they may be unaware of the danger in inappropriate use of these medications. We recommend locking the medications up in a lockbox or other secure area and limiting the individuals with access to this area.

The State of New Mexico Medical Boards and the Board of Pharmacy monitor prescriptions for narcotics and certain other medications very closely due to the "opioid death epidemic". Because of the mandates in place, we must monitor how the prescriptions are taken, where they are filled, and your Pharmacy will also be monitoring. We cannot provide more than one month of narcotics, and they usually will not be filled by the pharmacy more than 3 days prior to the refill date. Prescriptions are sent electronically, with security codes to the pharmacy, and cannot be called in by phone. Please be sure to notify us during office hours if you will need a refill, or this may be delayed. We hope you understand we want to treat your pain, but are also under stringent oversight to assure narcotics are prescribed safely, and the State requires that Narcan prescription be provided to every patient who receives a narcotic medication.

# Let your family and friends know about your pain

Your family and friends need to know about your pain so they can help you. If you are very tired, or experiencing a lot of pain, they can call your doctor or nurse for you. A better understanding of the pain you are experiencing can also help them recognize how and why you may be acting differently.

#### Practice pain control

- Take your pain medicine as prescribed by your doctor. If you have pain all the time, your doctor
  may suggest that you take your pain medicine on a set schedule. If you are on a set schedule,
  take the pain medicine as prescribed, rather than waiting to feel like you need it. Pain is harder
  to control and manage if you wait until your pain is severe before taking medicine.
- Try deep breathing, yoga, or other ways to relax. This can help reduce muscle tension, anxiety, and pain.
- For relaxation exercises, visit <u>Learning to Relax</u> on the National Cancer Institute's web site at: www.cancer.gov/about-cancer/coping/feelings/relaxation.
- Ask to meet with a pain or palliative care/ Pain management specialist. This person may be an oncologist, anesthesiologist, neurologist, neurosurgeon, nurse, or pharmacist who will talk with you about ways to control your pain.
- Tell your doctor if your pain changes significantly. Your dosage and or frequency may need to be changed.

Other resources: NCl's book, <u>Pain Control: Support for People with Cancer</u>, provides more tips about how to control pain from cancer and its treatment. Available at <u>cancer.gov</u> or <a href="https://www.cancer.gov/publications/patient-education/paincontrol.pdf">https://www.cancer.gov/publications/patient-education/paincontrol.pdf</a>

# Sexual Changes

Some types of chemotherapy can cause sexual changes. These changes are different for women and men.

In women, chemotherapy may damage the ovaries, which can cause changes in hormone levels. Hormone changes can lead to problems like vaginal dryness and early menopause.

In men, chemotherapy can cause changes in hormone levels, decreased blood supply to the penis, or damage to the nerves that control the penis, all of which can lead to impotence.

Whether or not you have sexual changes during chemotherapy depends on if you have had these problems before, the type of chemotherapy you are getting, your age, and whether you have any other illnesses. Some problems, such as loss of interest in sex, are likely to improve once chemotherapy is over.

#### Problems for women include:

Symptoms of menopause (for women not yet in menopause). These symptoms include:

- Hot flashes
- Vaginal dryness
- Feeling irritable
- Irregular or no menstrual periods
- Bladder or vaginal infections
- Vaginal discharge or itching

- Being too tired to have sex or not being interested in sex
- Feeling too worried, stressed, or depressed to have sex

#### Problems for men include:

- Not being able to reach climax
- Impotence (not being able to get or keep an erection)
- Being too tired to have sex or not being interested in sex
- Feeling too worried, stressed, or depressed to have sex

### Ways to manage

For women, talk to your doctor or nurse about:

- **Sex:** Ask your doctor or nurse if it is okay for you to have sex during chemotherapy. Most women can have sex, but it is a good idea to ask.
- **Birth control**: It is very important to prevent pregnancy while undergoing chemotherapy, and for a year after finishing your course. Chemotherapy can hurt the fetus, especially in the first three months of pregnancy. If you have not yet gone through menopause, talk with your doctor or nurse about your birth control methods, and ways to keep from getting pregnant. They may suggest that you use two forms of birth control.
- **Medications**: Talk with your doctor, nurse or pharmacist about medications that help with sexual problems. Medications can include products that relieve vaginal dryness, vaginal creams or suppositories to reduce the chance of infection.

Talk with your doctor or nurse about ways to relieve vaginal dryness and prevent infection.

#### To prevent infections:

- Wear cotton underwear or underpants, and pantyhose with cotton linings.
- Do not wear tight pants or shorts.
- Use a water-based vaginal lubricant (such as K-Y Jelly® or Astroglide®) when you have sex. If sex is still painful because of dryness, ask your doctor or nurse about medications that could help restore moisture in your vagina.
- When you have low blood counts, avoid intercourse due to risk of infection.

#### You can cope with hot flashes by:

- Dressing in layers. Wear a sweater or jacket that you can take off when needed.
- Being active. Add walking, biking, swimming, or other types of exercise to your daily routine.

#### Reducing stress:

- Regular exercise
- Yoga
- Meditation, or other relaxation exercises

For relaxation exercises, visit Learning to Relax on the National Cancer Institute's web site at: <a href="https://www.cancer.gov/about-cancer/coping/feelings/relaxation">www.cancer.gov/about-cancer/coping/feelings/relaxation</a>.

For men, talk with your doctor or nurse about:

- **Sex:** Ask your doctor or nurse if it is okay for you to have sex during chemotherapy. Most men can have sex, but it is a good idea to ask. Also, ask if you should use a condom when you have sex, since traces of chemotherapy may be in your semen.
- **Birth control**: It is very important that your spouse or partner not get pregnant while you are getting chemotherapy. Chemotherapy can damage your sperm and cause birth defects.

If you are having sex less often, try activities that make you feel close to each other.

Be open and honest with your spouse or partner. Talk about your feelings and concerns. Explore new ways to show love. You and your spouse or partner may want to show your love for each other in new ways while you go through chemotherapy. For instance, if you are having sex less often, you may want to hug and cuddle more, bathe together, give each other massages or find other activities that make you feel close to each other.

Talk with a doctor, nurse, social worker, or counselor. If you and your spouse or partner are concerned about sexual problems, you may want to talk with someone who can help. This person can be a psychiatrist, psychologist, social worker, marriage counselor, sex therapist, or clergy member.

Ways to learn more American Cancer Society Offers a variety of services to people with cancer and their families. Call: 1-800-ACS-2345 (1-800-227-2345) Visit: <a href="https://www.cancer.org">www.cancer.org</a>

# Skin and Nail Changes

Some types of chemotherapy can damage the fast-growing cells in your skin and nails. While these changes may be painful and annoying, most are minor and do not require treatment. Many of them will get better once you have finished chemotherapy. However, major skin changes need to be treated right away because they can cause lifelong damage.

### Minor skin changes may include:

- Itching, dryness, redness, rashes, and peeling
- Sensitivity to the sun (when you burn very quickly). This problem can happen even to people who have very dark skin color.
- Hyperpigmentation, a problem that results in dark patches on your skin or a darker skin color.
   Dark patches may occur: Around your joints Under your nails In your mouth Along the vein used to give you chemotherapy Under tape or dressings In your hair

Other nail problems. Besides becoming darker, your nails may also turn yellow or become brittle and cracked. Sometimes your nails will loosen and fall off, but new nails will grow back in.

#### Causes of major skin effects:

Radiation recall. Some chemotherapy causes skin in the area where you had radiation therapy to turn red. The color can range from very light to bright red. Your skin may blister, peel, or be very painful.

Chemotherapy leaking from your IV. You need to let your doctor or nurse know right away if you have burning or pain when you get IV chemotherapy.

Allergic reactions to chemotherapy. Some skin changes mean that you are allergic to the chemotherapy. Let your doctor or nurse know right away if you wheeze or have trouble breathing along with:

- Sudden and severe itching
- Rashes
- Hives

Let your doctor or nurse know right away if you have burning or pain when you get IV chemotherapy.

Ways to manage Itching, dryness, redness, rashes, and peeling:

Sprinkle yourself with cornstarch. Î Take quick showers or sponge baths instead of long, hot baths.

Pat, rather than rub, yourself dry after bathing.

Wash with a mild, moisturizing soap.

Put on cream or lotion while your skin is still damp after washing.

Tell your doctor or nurse if this does not help.

Do not use perfume, cologne, or aftershave lotion that has alcohol.

Take a colloidal oatmeal bath when your whole body itches. Colloidal oatmeal is a special powder you add to bath water.

Acne-type rash can occur with biologicals and targeted medicines. (Eg. Cetuximab, TKI's)

To help with rashes, consider these recommendations:

Keep your face clean and dry.

Ask your doctor or nurse if you can use medicated creams or soaps and which ones to use.

Sensitivity to the sun. Avoid direct sunlight. During the summer, the sun tends to be the strongest from 10 a.m. until 4 p.m. Use sunscreen lotion with an SPF (skin protection factor) of 15 or higher. Or use ointments that block the sun's rays, such as those with zinc oxide.

Keep your lips moist with a lip balm that has an SPF of 15 or higher.

Wear light-colored pants, long-sleeve cotton shirts, and hats with wide brims.

Do not use tanning beds.

#### Radiation recall:

Protect the area of your skin that received radiation therapy from sun exposure.

Place a cool, wet cloth where your skin hurts.

Wear clothes that are made of cotton or other soft fabrics. This includes your underwear (bras, underpants, and t-shirts).

Let your doctor or nurse know if you think you have radiation recall.

**Nail problems**: Wear gloves when washing dishes, working in the garden, or cleaning the house. Let your doctor or nurse know if your cuticles are red and painful.

# Urinary, Kidney, or Bladder Changes

Some types of chemotherapy damage cells in the kidneys and bladder.

## Problems may include:

- Burning or pain when you begin to urinate or after you empty your bladder
- Frequent, more urgent need to urinate
- Not being able to urinate
- Not able to control the flow of urine from the bladder (also called incontinence)
- Blood in the urine
- Fever
- Chills
- Urine that is orange, red, green, or dark yellow or has a strong medicine odor
- Some kidney and bladder problems will go away after you finish chemotherapy.
- Other problems can last for the rest of your life.

Drink plenty of fluids if you are getting chemotherapy that can damage the bladder and kidneys.

## Ways to manage:

You will have regular lab tests. Your doctor or nurse will take urine and blood samples to check how well your bladder and kidneys are working.

Drink plenty of fluids. Fluids will help flush the chemotherapy out of your bladder and kidneys. Limit drinks that contain caffeine, such as black tea, coffee, and some cola products.

Talk to your doctor or nurse. Tell them if you have any of the problems listed above.

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# Other Side Effects

Some types of chemotherapy can make you feel like you have the flu. This is more likely to happen if you get chemotherapy along with immunotherapy.

## Flu-like symptoms may include:

- Muscle and joint aches
- Headache
- Fatigue
- Nausea
- Fever
- Chills
- Appetite loss

These symptoms may last from one to three days.

An infection or the cancer itself can also cause them.

Let your doctor or nurse know if you have any of these symptoms.

#### Fluid retention:

Fluid retention is a buildup of fluid caused by chemotherapy, hormone changes caused by treatment, or your cancer. It can cause your face, hands, feet, or stomach to feel swollen and puffy. Sometimes fluid builds up around your lungs and heart, causing coughing, shortness of breath, or an irregular heartbeat. Fluid can also build up in the lower part of your belly, which can cause bloating.

### You and your doctor or nurse can help manage fluid retention by:

- Weighing yourself at the same time each day, using the same scale. Let your doctor or nurse know if you gain weight quickly.
- Avoiding table salt or salty foods.
- Limiting the amount of liquids you drink.

If you retain a lot of fluid, your doctor may prescribe medicine to get rid of the extra fluid.

#### Eye Changes

<u>Trouble wearing contact lenses</u>. Some types of chemotherapy can bother your eyes and make wearing contact lenses painful. Ask your doctor or nurse if you can wear contact lenses while getting chemotherapy.

#### Blurry vision

Some types of chemotherapy can clog your tear ducts, which can cause blurry vision and watery eyes. This can happen with chemotherapy like taxanes (Docetaxel, etc.)

If your vision gets blurry or your eyes water more than usual, tell your doctor or nurse.

# Immunotherapy-Related Adverse Effects (irAE)

## A summary of key information

The immune system and cancer:

- The immune system consists of many different components in the body.
- Some act as physical/chemical barriers (skin, cornea, membranes in the respiratory tract, gastrointestinal tract, urinary tract and reproductive tract).
- Others make and/or circulate specialized immune cells (the lymphatic system, bone marrow, spleen and thymus gland).
- The role of the immune system is to defend the body against threats, including microorganisms (bacteria, viruses, fungi) and cancer cells.
- After the physical/chemical barriers of the body, the next line of defense comprises white blood cells (leucocytes) that look for, and attack, microorganisms or abnormal cells (including cancer cells). T cells are white blood cells that play an important part in the acquired immune response in which each T cell learns, remembers and is specific to a particular antigen. T cells are activated via a "lock and key" mechanism enabling them to recognize, attack and kill cancer cells.

Many cancers are probably prevented by immune system surveillance and destruction of abnormal cells, but cancer cells can outwit the immune system in various ways.

# The concept of immuno-oncology

While chemotherapy or tumor-targeted drugs directly affect the growth and proliferation of tumor cells, immuno-oncological drugs harness the body's natural anti-cancer immune response to attack and destroy the cancer.

- Manipulation of immune checkpoints is at the leading edge of immuno-oncology.
- **Immune checkpoints** are designed to turn off the immune response to prevent autoimmunity and damage to healthy cells, but cancer hijacks these mechanisms by "deactivating" T cells once they have recognized the cancer, preventing attack and destruction of a cancer cell.
- **Checkpoint** inhibitors such as CTLA-4 inhibitors and **PD-1 pathway inhibitors** (two types already available in the clinic) or PD-L1 inhibitors (one type available in the clinic) prevent this deactivation and increase the body's anti-tumor immune response.

How does modern immunotherapy differ from chemotherapy and tumor-targeted drugs?

- Chemotherapy involves the use of one or more drugs to destroy tumor cells, based on the fact
  that these cells typically divide rapidly. Side effects are caused by damage to normal cells,
  especially those that also divide rapidly, such as cells in the bone marrow, hair follicle and
  gastrointestinal tract.
- Tumor-targeted drugs specifically act against molecular targets in cancer cells identified by tissue and blood samples. These drugs are used to treat some types of cancer in selected patients based on molecular characteristics of their tumors.

In general, it is expected that these drugs have fewer side effects on normal cells than chemotherapy does, but side effects from tumor-targeted drugs could also be substantial and depend largely on what each drug targets.

Because modern immunotherapy with checkpoint inhibitors blocks the body's natural safeguards that prevent immune overactivation, it can also affect normal tissues and cause autoimmune side effects. These comprise a different spectrum of events compared with those associated with chemotherapy and tumor-targeted drugs and require different management strategies.

## What are the side effects of immunotherapy?

- Immune-related side effects arising from treatment with checkpoint inhibitors can affect any organ or tissue, but most commonly affect the skin, colon, lungs, liver and endocrine organs (such as the pituitary gland or thyroid gland).
- Most of these side effects are mild to moderate and reversible if detected early and addressed appropriately, so the most important action you can take is to tell your doctor or oncology team of any new or worsening symptoms, or any symptoms that are worrying you.
- Side-effects of checkpoint inhibitor treatment typically appear within a few weeks or months of starting treatment, but they can arise at any time during treatment as early as days after the first infusion, but sometimes as long as 1 year after treatment has finished.
- The most common side effects for CTLA-4 inhibitors and PD-1/PD-L1 pathway inhibitors are skin symptoms (like rash and itching), while gastrointestinal symptoms (like diarrhea) seem to be more common with CTLA-4 inhibitors and lung symptoms and thyroid gland dysfunction seem to be more common with PD-1/PD-L1 pathway inhibitors.

### How will immunotherapy-related side effects be managed?

Checkpoint inhibitor-related side effects all are managed according to some basic common principles:

**Grade 1 (mild severity) or Grade 2 (moderate severity)** events generally are managed symptomatically, without interrupting or permanently stopping treatment.

- Patients with persistent Grade 2 symptoms may need to skip one or more treatment doses (as well as receiving symptomatic treatment), until their symptoms have improved.
- For patients with Grade 3 (severe) or Grade 4 (very severe) symptoms, treatment will typically be discontinued and referral to a specialist for example, a dermatologist for severe skin symptoms will usually be made.
   Oral or intravenous corticosteroids, or other immunosuppressive drugs, are used for severe or persistent side effects; their use does not appear to compromise the efficacy of treatment with checkpoint inhibitors.

If you must permanently stop treatment with an immune checkpoint inhibitor, after its course ends this should not negatively affect how your cancer responds since your immune system should be activated against the tumor cells.

# Common Immunotherapy drugs approved by the FDA

| DRUG TYPE                              | EXAMPLES               |
|--|------------------------|
| CTLA-4 inhibitors                      | lpilimumab             |
| PD-1 inhibitors (targeting the "lock") | Nivolumab              |
|  | Pembrolizumab          |
| PD-L1 inhibitors (targeting the "key") | Atezolizumab           |
|  | Avelumab               |
|  | Durvalumab             |
| Combination therapy                    | lpilimumab + nivolumab |

Image Source: **ESMO Patient Guide Series** 

# How does modern immunotherapy differ from chemotherapy and tumor-targeted drugs?

Chemotherapy involves the use of one or more drugs to destroy tumor cells directly or stop cancer growth by inhibiting cancer cells ability to multiply.

Chemotherapy is designed to affect cancer cells to a greater extent than normal cells, since cancer cells typically divide and multiply rapidly; however, this desired "selectivity" is not perfect, because normal cells also need to divide and multiply to replace themselves as they age – and some normal cells also divide rapidly, such as cells in the bone marrow, those lining the gastrointestinal tract, and cells in the hair follicles.

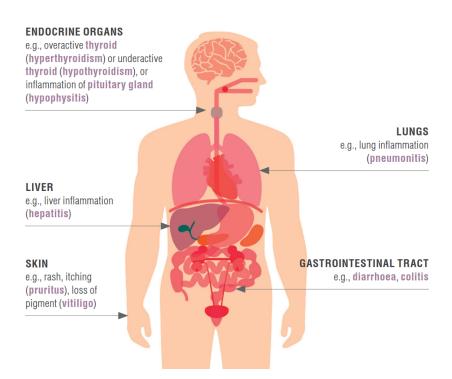
This is the reason for some of the common side effects from chemotherapy, such as hair loss, nausea and vomiting, reduced white blood cell counts (leucopenia, neutropenia), reduced red blood cell counts (anemia), reduced platelet counts (thrombocytopenia), diarrhea, and mucositis. Many of these side effects go away after chemotherapy ends and normal cells recover.

Different types of chemotherapy drugs may produce different ranges of side effects. Tumor-targeted drugs are used for treatment of some cancer types in selected patients based on molecular characteristics of tumors determined by tissue and blood analysis.

Tumor-targeted drugs can also cause side effects and their side effects profile depends largely on what the drug targets. The most common side effects from these drugs are diarrhea, liver problems, skin problems, heart problems and high blood pressure. Because many of tumor-targeted drugs are quite new, it is still not known if they can cause long-term side effects.

Unlike chemotherapy, which directly attacks tumor cells or tumor-targeted drugs that act against molecular targets in cancer cells, modern immunotherapy with checkpoint inhibitors works "indirectly", by harnessing the patient's own immune system. Because it blocks the body's natural safeguards that prevent immune overactivation, however, immunotherapy can also affect normal tissues and cause side effects

# Side effects of Immunotherapy:



Side effects to checkpoint inhibitor therapy most often affect the skin, colon, endocrine organs (such as the pituitary gland or thyroid gland), liver and lungs.

Image Source: ESMO Patient Guide Series

# What symptoms should I look out for?

Immune-related side effects (sometimes referred to as immune-related adverse effects or irAEs) arising from treatment with checkpoint inhibitors can affect any organ or tissue, but most commonly affect the skin, colon, lungs, liver and endocrine organs (such as the pituitary gland or thyroid gland)

Most immune-related side effects are mild to moderate. They are also often reversible if detected early and addressed appropriately, so you should always mention any symptoms that are worrying you to your oncology team – as soon as you notice them. They will be monitoring your progress and testing your blood for signs of any side-effects without obvious symptoms in their early stages. Because side-

effects to checkpoint inhibitor treatment can arise at any time during treatment – and sometimes also after treatment has finished – your oncology team will also advise you to look out for any of the following symptoms, and to notify them accordingly

- General: fatigue is a common side effect in patients treated with checkpoint inhibitors. Although its cause is poorly understood, it is important to exclude thyroid, pituitary, and other endocrine disorders.
- Skin: extensive rash or itching.
- Gastrointestinal: diarrhea especially containing blood or mucus, or severe abdominal pain.
- Endocrine: fatigue, weight loss, nausea/vomiting, excessive thirst or appetite, excessive and/or frequent urination.
- Respiratory: shortness of breath, cough.
- Any of these less common symptoms: headache. confusion. muscle weakness or pain. numbness. painful or swollen joints. unexplained fever. tendency to bruise easily.

## When are these side effects most likely to appear and how common are they?

Immune-related side effects to checkpoint inhibitor therapy typically occur quite early – mostly, within weeks to three months after treatment starts; however, first onset of side effects has been recorded as early as days after start to as long as one year after treatment has finished (Haanen et al., 2017).

It is thought that the timeline for immune-related side effects mirrors the evolution of the body's immune response to cancer as it is boosted by checkpoint inhibitor therapy – and eventual overactivation of this response that produces autoimmunity.

While gastrointestinal symptoms tend to be more common with CTLA-4 inhibitors, lung or thyroid symptoms seem to be more common with PD-1 inhibitors.

| AFFECTED ORGAN(S)      | CTLA-4 INHIBITORS | PD-1/PD-L1 INHIBITORS |  |  |
|------------------------|-------------------|-----------------------|--|--|
| Skin                   | Skin              |                       |  |  |
| Rash                   | 24%               | 15%                   |  |  |
| Itching                | 25%-35%           | 13%-20%               |  |  |
| Gastrointestinal tract |                   |                       |  |  |
| Diarrhoea              | 27%-54%           |                       |  |  |
| Colitis                | 8%-22%            | Very low              |  |  |
| Lungs                  |                   |                       |  |  |
| Cough/breathlessness   | Vory low          | 20%-40%               |  |  |
| Pneumonitis            | Very low          | 2%-4%                 |  |  |
| Liver                  | 5%-10%            | 5%-10%                |  |  |
| Endocrine organs       |                   |                       |  |  |
| Thyroid effects        | 1%-5%             | 5%-10%                |  |  |
| Hypophysitis           | 1%                | Very rare             |  |  |

Estimated frequencies of the most common side effects to different types of checkpoint inhibitors vary but the most common events across both types of therapies involve symptoms in the skin. The majority of these side effects are mild and reversible (Adapted from Haanen et al., 2017).

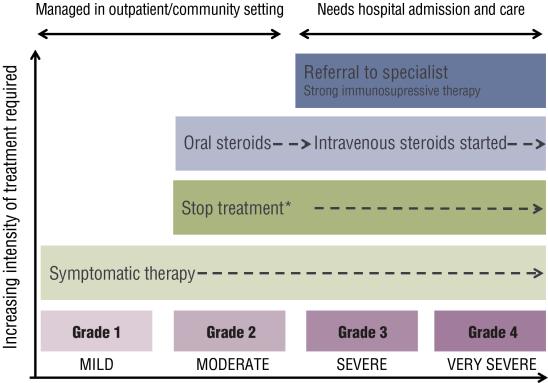
Image Source: **ESMO Patient Guide Series** 

# How will immunotherapy-related side effects be managed?

The principles for management of checkpoint inhibitor-related side effects generally are to manage Grade 1 or Grade 2 events by treating the symptoms, without interrupting or permanently stopping treatment.

Patients with persistent Grade 2 symptoms may need to skip one or more treatment doses and also receive treatment for their symptoms, until their symptoms have subsided or resolved.

For patients with Grade 3 or Grade 4 symptoms, treatment typically will be stopped and referral to a specialist will be arranged – for example, a dermatologist for severe skin symptoms.



\* For some side effects, treatment can be restarted when they subside

# Increasing grade of side effect

The general principle for managing side effects from treatment with checkpoint inhibitors is firstly, to identify symptoms early and address them promptly with treatment for symptoms and possibly oral steroids. Only if symptoms worsen will you be admitted to hospital for treatment with intravenous steroids or other immunosuppressive therapy. © Stéphane Champiat MD, PhD

Image Source: ESMO Patient Guide Series

Management of Common Immunotherapy Side effects

|                                     | GRADE   | SYMPTOMS  | MANAGEMENT   |  |
|-------------------------------------|---|---|--|--|
| .ts                                 | 1   | Rash covering less than 10% of <b>BSA</b> with or without symptoms. | Topical moisturising cream/ointment, oral or topical antihistamines for itching (if present) and/or topical corticosteroid cream (mild strength); checkpoint inhibitor treatment can continue.   |  |
|                                     | 2   | Rash covering 10%—30% of <b>BSA</b> with or without symptoms.       | Topical moisturising cream/ointment, oral or topical antihistamines for itching (if present) and/or topical corticosteroid cream (medium strength); checkpoint inhibitor treatment can continue.   |  |
| Skin side effects<br>(rash/itching) | Self-help measures for Grade 1/2 (mild-to-moderate) symptoms are: avoid contact with skin irritants and exposure to sun |   |  |  |
| Skin (ras                           | 3   | Rash covering less than 30% of <b>BSA</b> with or without symptoms. | Topical moisturising cream/ointment, oral or topical antihistamines for itching (if present) and/or topical corticosteroid cream (high strength); plus intravenous corticosteroids; checkpoint inhibitor treatment will be withheld, but may be restarted if symptoms reduce to Grade 1 or mild Grade 2. |  |
|                                     | 4   | Rash covering over 30% BSA with infection or other complications.   | Intravenous corticosteroids and<br>urgent specialist review; checkpoint<br>inhibitor therapy must be discontinued<br>permanently.  |  |

Image Source: ESMO Patient Guide Series

|  | GRADE   | SYMPTOMS  | MANAGEMENT   |
|--|---|---|--|
| le effects<br>itis)                                  | 1   | Fewer than three liquid stools per day more than before treatment started, feeling well.  | Anti-diarrhoeal medication (e.g. loperamide), and oral electrolyte supplementation if required; checkpoint inhibitor treatment can continue.   |
|  | 2   | Four to six liquid stools per day more<br>than before treatment started, or<br>abdominal pain, or blood in stool, or<br>nausea, or night-time symptoms.   | Oral corticosteroids and further tests<br>(e.g. sigmoidoscopy/colonoscopy);<br>checkpoint inhibitor treatment must be<br>withheld until symptoms resolve.  |
| rointestinal side ef<br>(diarrhoea/colitis)          | Self-help measures for Grade 1/2 (mild-to-moderate) diarrhoea/colitis are: drink plenty of fluids and avoid high-fibre/lactose diet |   |  |
| Gastrointestinal side effects<br>(diarrhoea/colitis) | 3 4   | Grades 3/4, over six liquid stools per<br>day more than before treatment started,<br>or symptoms occurring within 1 hour<br>of eating; also applies to patients with<br>Grade 1/2 stool frequency who have<br>other symptoms such as dehydration,<br>fever or a rapid heart rate. | Hospital admission, intravenous corticosteroids and further tests (e.g. sigmoidoscopy/colonoscopy if not already done); if there is no response to corticosteroids, strong immunosuppressive drugs (e.g., infliximab) can be used — checkpoint inhibitor therapy must be discontinued permanently. |
|  | 1   | <ul> <li>None; based on findings from<br/>x-ray examination.</li> </ul>   | <ul> <li>Monitored every two to three days, tests<br/>to rule out other causes; checkpoint<br/>inhibitor treatment may be delayed.</li> </ul>  |
| ng side effects<br>oneumonitis)                      | 2   | Breathlessness, cough, chest pain.  | Antibiotics (if infection suspected),     oral corticosteroids if no improvement     on antibiotics or no infection found,     further tests (including CT scan and     bronchoscopy); checkpoint inhibitor     treatment will be withheld.  |
| Lung<br>(pne   | 3   | Worsening symptoms, difficulty breathing.   | Hospital admission, intravenous  |
|  | 4   |   | corticosteroids, other stronger immunosuppressive drugs if no improvement; checkpoint inhibitor treatment must be discontinued permanently.  |

Image Source (this page and next): ESMO Patient Guide Series

|                                   |           | GRADE | SYMPTOMS  | MANAGEMENT  |
|-----------------------------------|-----------|-------|---|---|
| Liver side effects<br>(hepatitis) |           | 1     | None; based on laboratory values from<br>blood tests of liver enzyme levels.  | <ul> <li>No immediate treatment necessary,<br/>blood tests repeated in one week's time;<br/>checkpoint inhibitor treatment can<br/>continue.</li> </ul>   |
|                                   |           | 2     | None; based on laboratory values from<br>blood tests of liver enzyme levels.  | Blood tests repeated every three days, further liver function tests done (if liver enzyme levels rising, oral corticosteroid treatment will be given); checkpoint inhibitor treatment will be withheld but may be restarted if symptoms improve (after corticosteroids have been gradually reduced).  |
| Liv                               |           | 3     | Grades 3/4, tiredness, feeling unwell,<br>mild joint or muscle pains, decreased<br>appetite/weight loss, nausea, itching,<br>rash, diarrhoea, bloating; may have few<br>or even no symptoms.  | Oral or intravenous corticosteroids,<br>depending on liver enzyme levels;<br>checkpoint inhibitor therapy will be<br>stopped.   |
|                                   |           | 4     |   | Hospital admission, intravenous corticosteroids and specialist review; checkpoint inhibitor treatment must be discontinued permanently.   |
| Endocrine side effects            | Thyroid   | -     | <ul> <li>For hyperthyroidism (usually transient and Grade 1 or 2), may be no symptoms if mild, various symptoms with increasing severity including nervousness, anxiety and irritability, mood swings, difficulty sleeping, persistent tiredness and weakness, sensitivity to heat, swelling in the neck from an enlarged thyroid gland, irregular and/or unusually fast heart rate (palpitations), twitching or trembling, weight loss.</li> <li>For hypothyroidism (usually Grade 1 or 2), may be no symptoms if mild, various symptoms with increasing severity including tiredness, sensitivity to cold, weight gain, constipation, depression, slow movements and thoughts, muscle aches and weakness, muscle cramps, dry and scaly skin, brittle hair and nails.</li> </ul> | <ul> <li>For symptomatic hyperthyroidism, treatment is initiated with beta-blockers; checkpoint inhibitor therapy will be interrupted until symptoms resolve.</li> <li>For hypothyroidism, treatment is with long-term hormone replacement therapy (with thyroid hormones, depending on severity) and oral corticosteroids if thyroid gland inflamed; checkpoint inhibitor therapy may be interrupted until symptoms resolve.</li> <li>Blood tests will be done regularly for both conditions to monitor levels of thyroid hormones.</li> </ul> |
|                                   | Pituitary | -     | For hypophysitis (usually Grade 1 or 2),<br>no symptoms if mild, or any/all of various<br>symptoms including headache, double<br>vision, excessive thirst, production of large<br>volumes of dilute urine, various hormonal<br>imbalances (and related symptoms).   | Oral or intravenous corticosteroids<br>and appropriate hormone replacement<br>therapy (depending on severity and which<br>set of hormones is affected); checkpoint<br>inhibitor therapy may be continued during<br>less severe (most) symptoms, but may be<br>withheld for more severe symptoms.  |

# **Food Tips**

### During cancer treatment

Once your treatment starts you need to try to eat well. Your body needs a healthy diet to function at its best. This is even more important if you have cancer. In fact, some cancer treatments work better in people who are well-nourished and are getting enough calories and protein.

### Try these tips:

- Don't be afraid to try new foods. Some things you may never have liked before may taste good during treatment.
- Choose different plant-based foods. Try eating beans and peas instead of meat at a few meals each week.
- Try to eat at least 2½ cups of fruits and vegetables a day, including citrus fruits and dark-green and deep-yellow vegetables. Colorful vegetables and fruits and plant-based foods contain many natural health-promoting substances.
- Limit the amount of salt-cured, smoked, and pickled foods you eat, but snack as needed during your cancer treatment. Your body often needs extra calories and protein to help you maintain your weight and heal as quickly as possible. If you're losing weight, snacks can help you meet those needs, keep up your strength and energy level, and help you feel better.

Try these tips to make it easier to add snacks to your daily routine:

- Eat small snacks throughout the day.
- Keep a variety of protein-rich snacks on hand that are easy to prepare and eat. These include
  yogurt, cereal and milk, half a sandwich, a bowl of hearty soup, and cheese and crackers. Avoid
  snacks that may make any treatment-related side effects worse. If you have diarrhea, for
  example, avoid popcorn and raw fruits and vegetables. If you have a sore throat, do not eat dry,
  coarse snacks or acidic foods.
- If you're able to eat normally and maintain your weight without snacks, then don't include them.

### Tips to increase calories and protein:

- Eat several small snacks throughout the day, rather than 3 large meals.
- Eat your favorite foods at any time of the day. For instance, eat breakfast foods for dinner if they appeal to you.
- Eat every few hours. Don't wait until you feel hungry.
- Try to eat high-calorie, high-protein foods at each meal and snack.
- Exercise lightly or take a walk before meals to increase your appetite.
- Drink high-calorie, high-protein beverages like milk shakes and canned liquid supplements.

| Some quick and easy snacks  |   |   |
|---|---|---|
| Angel food cake   | Gelatin made with juice,<br>milk or fruit | Popcorn, pretzels   |
| Cereal (hot or cold)  | Granola or trail mix                      | Puddings, custards  |
| Cheese (aged or hard cheese, cottage cheese, cream cheese and more) | Homemade milkshakes and smoothies         | Sandwiches such as egg salad, grilled cheese or peanut butter |
| Cookies   | Ice cream, sherbet and frozen yogurt      | Soups (broth-based or hearty)                                 |
| Crackers  | Juices                                    | Sports drinks   |
| Dips made with cheese, beans,                                       | Milk by itself, flavored, or with         | Vegetables (raw or cooked) with                               |
| yogurt or peanut butter   | instant breakfast powder                  | olive oil, dressing, or sauce                                 |
| Eggnog  | Muffins                                   | Yogurt (low-fat or Greek)                                     |
| Fruit (fresh, frozen, canned, dried)                                | Nuts, seeds, and nut butters              | Microwave snacks  |

| High-protein foods                |   |
|-----------------------------------|---|
| Milk products                     | <ul> <li>Add grated cheese to baked potatoes, vegetables, soups, noodles, meat and fruit.</li> <li>Use milk in place of water for hot cereal and soups.</li> <li>Add Greek yogurt, powdered whey protein, or cottage cheese to favorite fruits or blended smoothies.</li> </ul>                               |
| Eggs                              | <ul> <li>Keep hard-boiled eggs in the refrigerator. Chop and add to salads, casseroles, soups and vegetables. Make a quick egg salad.</li> <li>All eggs should be well-cooked to avoid the risk of harmful bacteria.</li> <li>Pasteurized egg substitute is a low-fat alternative to regular eggs.</li> </ul> |
| Meats, poultry and fish           | <ul> <li>Add cooked meats to soups, casseroles, salads, and omelets.</li> <li>Mix diced or flaked cooked meat with sour cream and spices to make dips.</li> </ul>   |
| Beans, legumes, nuts<br>and seeds | <ul> <li>Sprinkle seeds and nuts on desserts like fruit, ice cream, pudding and custard. Also serve on vegetables, salad and pasta.</li> <li>Spread peanut or almond butter on toast and fruit or blend in a milk shake.</li> </ul>   |

| High-calorie foods |  |
|--------------------|--|
| Butter             | <ul> <li>Melt over potatoes, rice, pasta and cooked vegetables</li> <li>Stir melted butter into soups and casseroles and spread on bread before adding other ingredients to your sandwich</li> </ul> |
| Milk products      | <ul> <li>Add whipping or heavy cream to desserts, pancakes, waffles, fruit and hot chocolate, fold it into soups and casseroles.</li> <li>Add sour cream to baked potatoes and vegetables</li> </ul> |
| Salad dressings    | <ul> <li>Use regular (not low-fat or diet) mayonnaise and salad dressing on<br/>sandwiches and as dips with vegetables and fruit.</li> </ul>   |
| Sweets             | <ul> <li>Add jelly and honey to bread and crackers</li> <li>Add jam to fruit</li> <li>Use ice cream as a topping on cake</li> </ul>  |

The following table shows eating-related side effects associated with radiation. Radiation can cause inflammation of the mucous lining of the GI tract and this causes can cause swelling and pain. These side effects can happen during or after treatment.

| Part of body being treated   | Eating-related side-effects that might happen during treatment   | Eating-related side-effects that might happen more than 90 days after treatment  |
|--|--|--|
| Brain, spinal column   | Nausea, vomiting   | Headache, tiredness  |
| Head or neck: tongue, voice box, tonsils, salivary glads, nasal cavity, pharynx (throat) | Sore mouth, troubled or painful swallowing, change in or loss of taste, sore throat, dry mouth, thick saliva | Dry mouth, damage to jaw<br>bone, lockjaw, changes in taste<br>and smell   |
| Chest: Lungs, esophagus, breast  | Trouble swallowing, heartburn, tiredness, loss of appetite   | Narrowing of the esophagus, chest pain with activity, enlarged heart, inflammation of the pericardium (the membrane around the heart), lung scarring or inflammation |

| Belly (abdomen): Large or small intestine, prostate, cervix, uterus, rectum, pancreas | Loss of appetite, nausea, vomiting, diarrhea, gas, bloating, trouble with milk products, changes in urination, tiredness | Diarrhea, blood in urine,<br>bladder irritation |
|---|--|---|
|---|--|---|

# Here are some tips on how to help protect yourself:

# Food-handling tips

- Wash your hands with warm, soapy water for 20 seconds before and after preparing food and before eating.
- Refrigerate foods at or below 40° F.
- Keep hot foods hot (warmer than 140° F) and cold foods cold (cooler than 40° F).
- Thaw meat, fish, or poultry in the microwave or refrigerator in a dish to catch drips. Do not thaw at room temperature.
- Use defrosted foods right away, and do not refreeze them.
- Rinse leaves of leafy vegetables one at a time under running water.
- Use different utensils for stirring foods and tasting them while cooking. Do not taste the food (or allow others to taste it) with any utensil that will be put back into the food.
- Throw away eggs with cracked shells.
- Throw out foods that look or smell strange. Never taste them!
- Use a clean knife to cut different foods.
- In the refrigerator, store raw meat sealed and away from ready-to-eat food.
- Keep foods separated on the countertops. Use a different cutting board for raw meats.
- Clean counters and cutting boards with hot, soapy water, or you can use a fresh solution made of 1-part bleach and 10 parts water. Moist disinfecting wipes may be used if they're made for use around food.
- When grilling, always use a clean plate for the cooked meat. Cook foods well
- Put a meat thermometer into the middle of the thickest part of the food to test for doneness. Test a thermometer's accuracy by putting it into boiling water. It should read 212° F.
- Cook meat until it's no longer pink and the juices run clear. The only way to know for sure that meat has been cooked to the right temperature is to use a food thermometer. Meats should be cooked to 160° F and poultry to 180° F.

# Grocery shopping

Do not use damaged, swollen, rusted, or deeply dented cans. Be sure that packaged and boxed foods are properly sealed.

- Choose unblemished fruits and vegetables.
- Do not eat deli foods. In the bakery, avoid unrefrigerated cream- and custard-containing desserts and pastries.
- Do not eat foods that are bought from self-serve or bulk containers.

- Do not eat yogurt and ice cream products from soft-serve machines.
- Do not use cracked or unrefrigerated eggs.
- Get your frozen and refrigerated foods just before you check out at the grocery store, especially during the summer months.
- Refrigerate groceries right away. Never leave food in a hot car.

# Dining out

- Eat early to avoid crowds.
- Ask that food be prepared fresh in fast-food restaurants.
- Ask for single-serving condiment packages, and avoid self-serve bulk condiment containers.
- Do not eat from high-risk food sources, including salad bars, delicatessens, buffets and smorgasbords, potlucks, and sidewalk vendors.
- Do not eat raw fruits and vegetables when eating out.
- Ask if fruit juices are pasteurized. Avoid "fresh-squeezed" juices in restaurants.
- Be sure that utensils are set on a napkin or clean tablecloth or placemat, rather than right on the table. If you want to keep your leftovers, ask for a container, and put the food in it yourself rather than having the server take your food to the kitchen to do this.

| High-fiber foods to choose more often |              |                          |
|---------------------------------------|--------------|--------------------------|
| Breads and Cereals                    | Serving Size | Dietary fiber (in grams) |
| Bran cereals                          | ½ cup        | 3-13                     |
| Popcorn                               | 2 cups       | 5                        |
| Brown rice                            | ½ cup        | 6                        |
| Whole-wheat bread                     | 1 slice      | 1-2                      |
| Whole-wheat pasta                     | ¼ cup        | 6                        |
| Wheat bran, raw                       | ¼ cup        | 6                        |
| Legumes                               |              |                          |
| Kidney Beans                          | ½ cup        | 8                        |
| Navy Beans                            | ½ cup        | 9                        |
| Nuts Beans                            | 1 ounce      | 1-3                      |
| Vegetables                            |              |                          |
| Broccoli                              | ½ cup        | 4                        |
| Brussels sprouts                      | ½ cup        | 3                        |
| Carrots                               | ½ cup        | 2                        |
| Corn                                  | ½ cup        | 5                        |
| Green peas                            | ½ cup        | 3                        |
| Potato with skin                      | 1 medium     | 3                        |
| Fruits                                |              |                          |
| Apple with peel                       | 1 medium     | 4                        |
| Banana                                | 1 medium     | 2                        |
| Blueberries                           | ½ cup        | 2                        |
| Pear with skin                        | 1 medium     | 5                        |

| Prunes       | 3        | 3 |
|--------------|----------|---|
| Orange       | 1 medium | 3 |
| Raisins      | ¼ cup    | 3 |
| Strawberries | 1 cup    | 3 |

Adapted from Eldridge B, and Hamilton KK, Editors, *The Complete Resource Kit for Oncology Nutrition*, Academy of Nutrition and Dietetics, 2013.

| What to eat of not eat when you have diarrhea*                            |  |  |
|---|--|--|
|   | Eat  | Food that may cause problems   |
| High protein  | Baked or broiled beef, pork, chicken, turkey, veal, fish   | Fried meats, high-fat cuts of meats, meats with gristle                    |
|   | Eggs, buttermilk, cheese, yogurt   | Dairy products other than buttermilk or yogurt                             |
| Breads, cereals, rice, and pasta  | Breads, rolls and pasta made from refined, white flour; converted or instant rice                                      | Whole grain breads and cereals like whole wheat, oat, and rye bran         |
|   | Refined cereals like farine,<br>Cream of Wheat, Cream of Rice,   | Shredded wheat Granola   |
|   | oatmeal, cornflakes  |  |
|   | Pancakes, waffles, cornbread, muffins, graham crackers   | Wild rice  |
| Fruits and vegetables   | Some soups made with vegetables listed here: cooked asparagus tips, beets, carrots, peeled zucchini, mushrooms, celery | Fresh, unpeeled fruit; pears; melon All other vegetables                   |
|   | Tomato paste, tomato puree, tomato sauce   |  |
|   | Bakes potato without skin  |  |
|   | Canned, frozen, or fresh fruit   |  |
| Drinks, desserts, and other   | Butter, margarine  | Desserts with nuts   |
| foods   | Mayonnaise, salad dressing,  | Coconut, dried fruit   |
|   | vegetable oil  | Chocolate, licorice  |
|   | Cake, cookies, flavored gelatin, desserts, sherbet   | Pickles  |
|   | Decaffeinated beverages  | Popcorn  |
|   | Salt, pepper, spices, and gravy as tolerated   | Foods with a lot of pepper, chili seasoning, or taco seasoning; hot sauces |
| + Adapted from Eldridge B, and Hamilton<br>Nutrition and Dietetics, 2013. | KK, Editors, The Complete Resource Kit for   | r Oncology/Nutrition, Academy of   |

| What to eat or not eat when you have a dry mouth* |  |  |
|---|--|--|
|   | Eat  | Food that may cause problems   |
| High protein                                      | Meats, poultry, and fish in sauces and gravies Casseroles, soups, and stews  | Dry meats, poultry, and fish without sauces  |
| Breads, cereals, rice, and pasta                  | Breads, rolls  Cooked and cold cereals, cereal with milk   | Dry breads, rolls  Pasta, rice  Pretzels, chips                                    |
|   | Rice soaked in gravy, sauce, broth, or milk  | Dry cereal   |
| Fruits and vegetables                             | Canned and fresh fruits that have a lot of moisture, like oranges and peaches  Vegetables in sauce   | Bananas, dried fruit Vegetables, unless in a sauce or with a high moisture content |
| Drinks, desserts, and other foods                 | Club soda, hot tea with lemon (decaf), fruit-ades, diluted juices, sports drinks  Commercial liquid nutrition supplements  Homemade milk shakes; ice cream, sherbet, pudding | Desserts with nuts Coconut, dried fruit Cookies, cake, pie, unless soaked in milk  |

| What to eat or not eat when you have mouth sores* |  |                                       |
|---|--|---------------------------------------|
|   | Eat  | Food that may cause problems          |
| High protein                                      | Ground, chopped, or blenderized meats, poultry, or fish            | Whole meats, poultry, fish, dry meats |
|   | Casseroles   |                                       |
|   | Egg, cheese, and bean dishes                                       |                                       |
|   | Milk shakes, yogurt, and commercial liquid nutritional supplements |                                       |

Nutrition and Dietetics, 2013.

| Breads, cereals, rice, and pasta  | Moistened breads  Cooked cereals, cold cereals soaked in milk  Pasta and rice in sauce   | Dry toast, hard rolls, dry crackers, English muffins, bagels  |
|-----------------------------------|--|---|
| Fruits and vegetables             | Cooked or blenderized fruits and vegetables  | Fresh fruits and vegetables (unless very ripe, soft, and juicy, like applesauce, bananas, and watermelon);citrus fruit, pineapple, and other acidic fruits Pickled fruit, raw and pickled vegetables Tomatoes |
| Drinks, desserts, and other foods | Fruit nectars  Flavored gelatin  Ice cream, sherbet, pudding  Butter, margarine, and  vegetable oils  KK, Editors, The Complete Resource Kit for | Carbonated drinks  Cookies and cakes unless soaked in milk  Crunchy snacks like pretzels and chips  Vinegar  Condiments like pepper, pepper sauces chili powder cloves, nutmeg, salsa                         |

<sup>+</sup> Adapted from Eldridge B, and Hamilton KK, Editors, The Complete Resource Kit for Oncology/Nutrition, Academy of Nutrition and Dietetics, 2013.

| What to eat or not eat when you have nausea |  |   |
|---|--|---|
|   | Recommended  | Avoid (do not eat)  |
| High Protein                                | Boiled or baked meat, fish, and poultry; cold meat or fish salad             | Fatty and fried meats, like sausage or bacon              |
|   | Eggs   | Fried eggs  |
|   | Cream soups made with low-fat milk   | Milk shakes (unless made with low-fat milk and ice cream) |
|   | Non-fat yogurt   |   |
| Breads, cereals, rice and pasta             | Saltines, soda-crackers, bread, toast, cold cereal, English muffins, bagels. | Doughnuts, pastries, waffles, pancakes, muffins           |
|   | Plain noodles, rice  |   |

|   | <u> </u>  |   |
|---|---|---|
| Fruits and vegetables                   | Potatoes (baked, boiled or mashed)  | Potato chips, French fries, hash browns   |
|   | Juices  | Breaded, fried or creamed   |
|   | Canned or fresh fruits,<br>vegetables as tolerated (do not<br>eat if appetite is poor or nausea<br>is severe)   | vegetables with strong odor   |
| Breads, cereal, rice and pasta          | Breads, bagels, muffins, rolls, cereals, crackers, noodles, pasta, potatoes and rice are safe to eat as long as they are purchased as wrapped, prepackaged items, not sold in self-service bins.                | Bulk-bin sources of cereals, grains and other foods   |
| Fruits and vegetables                   | Raw vegetables and fruits and fresh herbs are safe to eat if washed under running water and lightly scrubbed with a vegetable brush   | Fresh salsas and salad dressings found in the refrigerated section of the grocery store. Choose shelf-stable salsa and dressings instead.  Any raw vegetable sprouts (including alfalfa, radish, broccoli or mung bean sprouts) |
| Drinks, desserts and other foods        | Cold fruit juice, decaffeinated soft drinks, iced decaf tea, sports drinks  Sherbet, fruit-flavored gelatin Pudding  Popsicles, juice bars, fruit ices  Butter or margarine in small amounts, fat-skimmed gravy | Alcohol Coffee Pie, ice cream, rich cakes Spicy salad dressings Olives  |
| Adapted from Eldridge B, and Hamilton K | K, Editors, The Complete Resource Kit for C   | Oncology Nutrition, Academy of Nutrition  |

and Dietetics, 2013.

| What to eat when you have trouble swallowing (pureed and thick-liquid diet) |   |  |
|---|---|--|
|   | Puréed thick-liquid diet  | Mechanical soft diet                             |
| Protein   | Thickened milk, yogurt without fruit, cottage cheese, sour cream Casseroles | Milk, yogurt, cheeses, sour<br>cream<br>All eggs |

|                                  | Soft-scrambled eggs Puréed meat, poultry and fish   | Ground meats and ground-meat casseroles, fish, sandwiches made with ground meats or spreads  |
|----------------------------------|---|--|
| Breads, cereals, rice and pasta  | Slurry of cooked cereals like<br>Cream of Wheat and Cream of<br>Rice  | Soft breads Graham crackers, cookies Soft cold cereals in milk Pancakes, waffles Pasta, rice   |
| Fruits and vegetables            | Puréed fruit and vegetables<br>without seeds and skins<br>Mashed potatoes                                       | Bananas Canned fruit Soft, well-cooked, or puréed vegetables   |
| Drinks, desserts and other foods | Thickened juices and nectars Thick milkshakes Thickened broths and cream soups Syrups, honey, butter, margarine | All beverages  Soft desserts that don't require much chewing (like ice cream, sherbet, flavored gelatin, pudding, custard), soft cakes and cookies  Syrups, honey, butter, margarine |

Adapted from Grant BL, Bloch AS, Hamilton KK, Thomson CA. *American Cancer Society Complete Guide to Nutrition for Cancer Survivors, 2<sup>nd</sup> Edition.* Atlanta, GA: American Cancer Society; 2010.

#### Diet after treatment:

<u>Nutrition after treatment ends</u> Most eating-related side effects of cancer treatments go away after treatment ends. Sometimes side effects like poor appetite, dry mouth, change in taste or smell, trouble swallowing, or weight changes last for some time. If this happens to you, talk to your cancer care team and work out a plan to deal with the problem.

# Tips for healthy eating after cancer:

- Check with your cancer care team for any food or diet restrictions.
- Ask your dietitian to help you create a nutritious, balanced eating plan.
- Choose a variety of foods from all the food groups. Try to eat at least 2½ cups of fruits and vegetables each day; include citrus fruits and dark-green and deep-yellow vegetables.
- Eat plenty of high-fiber foods, like whole-grain breads and cereals.
- Buy a new fruit, vegetable, low-fat food, or whole-grain product each time you shop for groceries.

• If you choose to drink alcohol, limit the amount to no more than 1 drink per day for women, and 2 for men. Alcohol is a known cancer-causing agent.

# How to Get the Most of Your Doctor Visits

Ask yourself, "How much do I want to know?"

It's OK to learn at your own pace. Only you know when you are ready to talk, when you want to learn more about your cancer, and how much detail you want.

You may want to know a lot about your illness. Some people feel more in control of what's going on when they know all the facts. Or you may want only small amounts of information. It upsets some people to be told too much at one time. They may feel stressed or overwhelmed by details. Some of these people might prefer to leave most decisions to their doctor. Tell your doctor how much or how little you want to know.

# Asking questions

Don't be afraid to ask questions. Many doctors wait for you to ask questions, but you may not even know what to ask. It's easy to forget the questions you or your loved ones may have. It helps to write them down as they come up, then take them with you when you go to the doctor's office. Here are some common questions people have about cancer:

- What kind of cancer do I have?
- What treatment do you suggest?
- Are there other treatments?
- How will these treatments help me?
- How might they hurt me? What are the risks?
- What medicines will I get? What are they for?
- How will I feel during treatment?
- What side effects, if any, should I watch for?
- Are there any side effects or unusual signs that I need to tell you about right away?
- What can be done about the side effects?
- What's the best time to call if I have a question or problem? How quickly can I expect to be called back?
- What should I do if I have a serious problem when your office is closed?
- Should I get a second opinion? From whom?
- How can I remember everything?

It's hard to remember all of the things you are told at each doctor's visit. It helps to have the same person there with you each time. They can remind you of questions you want to ask and help you recall what the doctor said.

It may also be easier to have this person talk to your loved ones about how you are doing. This will help them know what's going on, but keep you from having to deal with a lot of questions. You might want your loved ones' help in making decisions, so keeping them up to date is a good idea.

Be sure you or your loved one writes down what your doctor tells you. You may even want to record your talk. Be sure to ask your doctor if it's OK first.

If you need more details after your doctor answers a question, say so. It may be helpful to ask the same question again in some other way. Sometimes, doctors use words that are hard to understand. If you don't understand something, ask your doctor to explain it. It may help to ask for pictures, websites, videos, or other things you can take home and look at on your own time.

When you get instructions from your doctor, write them down. Make sure you understand them before you leave the office. Then follow them exactly. It's OK to call the doctor's office if you have more questions later. Nurses can often help you, too.

Above all, your doctor should take your questions seriously. They should want to know about your concerns and not make you feel rushed. If your doctor does not respond this way, let them know.

# Make sure all your doctors talk with each other.

You will often have more than one doctor, and each one should know what's being done. Make a list of all your doctors' names, specialties, phone numbers, and addresses. Give a copy of this list to each doctor who's on it. This will make it easier for them to talk with each other and share reports and medical records.

You may have to sign forms saying it's OK for them to share information and talk about your case. This is done to protect your privacy. When you visit a doctor, ask if they have talked with your other doctors or gotten their reports.

#### It's your health care team.

You are a key member of your health care team. Your team will count on you to be an active partner. This means going to office visits, taking medicines as prescribed, telling your doctor or nurse about any problems or concerns you're having, and asking lots of questions.

Taking an active role in your care will help you learn what you need to know. It will also help make sure that everyone is working with you to fight the cancer. For some, it takes time to learn how to be an active team member, but you may be surprised at how good you and your loved ones will get at this over time.

You may never know as much about cancer and its treatment as your doctor, but you and your loved ones are the only ones who can decide what's best for you. As part of your team, keep in mind that you have a key part to play in your care.

If you need to learn more about how to be an active member of your health care team or have questions about your cancer or cancer treatment, please call us anytime, day or night, at NMHOS call number cited at the front of this booklet. American Cancer society has a helpline as well. 1-800-227-2345.

# **Treatment Options**

A second opinion: You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

**Taking part in a clinical trial:** Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomized trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse or get a second opinion. If you decide to take part, you can withdraw at any time. Consider going to the National Institutes of Health clinical trials database to learn more about clinical trials: https://clinicaltrials.gov/

# Helpful Websites

Cancer information on the Internet comes from many different sources – expert health organizations, government agencies, universities, merchants, interest groups, the general public, and scam artists. Anyone can post any kind of information online and some people may be passing along information that's limited, inaccurate, or just plain wrong. Some even try to deceive you.

Scam artists and other dishonest people use the Internet for 2 main reasons: low cost and relative anonymity (no one knows who they are). What's more, the message or product gets out to people all over the world.

The nature of the web makes it easier to mislead people. For example, if you saw a sign in front of a small, run-down store that claimed it was the largest supplier of medical devices in the United States, you'd probably be suspicious right away. But if you saw a professional-looking site on the Internet making the same claim, you might have a harder time deciding if it was real.

This is not to say that you shouldn't trust anything on the Internet – just that you have to choose your sources carefully. Even on trusted, highly regarded websites, it's important to note that the health information is just general information that might not apply to you at all. **Always remember that the information found online should not take the place of medical advice.** If you have a health-related problem, please talk to a doctor. There's no other way to get the same experience and care as sitting down with a health care provider who can look at your health history, your unique medical situation, examine you, and talk with you about how you've been feeling.

Searches can give you commercial results too, touting some new great drug that cures all. We get asked about various different herbals curing cancer. Beware of such sites.

Is the site run or paid for by an individual or by an organization? What type of organization – business, government agency, or non-profit organization?

Any honest, health-related site should make it easy for you to find out who is responsible for the information on it. Often this can be found by clicking on "About Us," which can usually be found at the top or bottom of the site's main (home) page.

You can get an idea about who runs a site by looking at the letters at the end of the URL address, called top level domain names.

- .edu means that the source of the information is part of an educational system (such as a college or university)
- .org usually means that the source is a non-profit organization
- .gov means that the source is a part of a national or state government
- .com or .biz usually means the site is run by a commercial (for-profit) or private source

Knowing whether the information came from a business, a university, or a non-profit group can be useful because it could give you some insight into why the individual or organization is providing that

information. There are other top-level domain names, but these are among the oldest in use that might apply to health information sources.

Although the US doesn't do it, other countries usually have a 2-letter code that comes after the end of the basic URL. For example, India uses *in* and Australia uses *au*. You might notice information from a government agency includes *.gov*.

It's important to know where information comes from, because while the general information might be good, treatment information, treatment availability, and cancer statistics in other countries can be very different from those of the US.

In the US, the most reliable sources of health information tend to be government agencies, hospitals, universities, and major public health and health advocacy organizations, such as the American Cancer Society. These groups use information that's reviewed by noted experts and updated often.

Who's funding the site should also be easy to figure out. It's important, because it can affect what's presented on the site and how it's presented. If the source is a commercial business, such as an advertiser or provider of a service or product, there may be some bias or prejudice in the information. Government sites, universities, and public health groups generally seek only to educate the reader. But even on non-profit websites, if the site is full of ads or is supported or funded by an outside company, it's important to ask yourself whether the information there might be biased in some way. This isn't always the case, but it should make you more cautious.

Make sure you know who is writing the recommendation and what their experience and/or credentials are. You don't want to take cancer treatment advice from a blogger or a layman. Make sure the information you use is up-to-date and well-referenced.

# Warning signs:

It may not be easy to get answers to the questions listed above. Even some reputable websites may fall short in certain areas. Another helpful way to size up a website is to look closely at what's there.

The US Federal Trade Commission (FTC) has developed a list of claims that should make you suspicious of a website:

- Claims of a "scientific breakthrough," "miraculous cure," "secret ingredient," or "ancient remedy"
- Claims that a product can cure a wide range of illnesses (No one product can do this.)
- Stories of people who've had amazing results, but no clear scientific data
- Claims that a product is available only from one source, especially if you must pay in advance
- Claims of a "money-back" guarantee (While this may make the product seem risk-free, it's often impossible to actually get your money back.)
- Websites that don't list the company's name, street address, phone number, and other contact information (It may exist only offshore, away from US laws and regulators.)

Problems in any of these areas should raise a red flag – a warning – to the user that the site may contain information that's not based on careful science and cannot be trusted. This may be especially important when looking at sites promoting complementary or alternative cancer treatments. Best, just ask your Physician.

#### We trust these cancer information websites:

American Society of Clinical Oncology (ASCO) patient information website: <a href="https://www.cancer.net/about-us/asco-answers-patient-education-materials">https://www.cancer.net/about-us/asco-answers-patient-education-materials</a>

National Comprehensive Cancer Network (NCCN): <a href="http://www.nccn.org">http://www.nccn.org</a>

Medline Plus: <a href="http://www.nlm.nih.gov/medlineplus/cancer.html">http://www.nlm.nih.gov/medlineplus/cancer.html</a>

American Cancer Society: <a href="http://www.cancer.org/index">http://www.cancer.org/index</a>

Liddy Shriver Sarcoma Initiative for sarcoma: <a href="http://sarcomahelp.org/index.html">http://sarcomahelp.org/index.html</a>

National Institutes of Health (NIH) website for clinical trials: https://clinicaltrials.gov/

#### Other Cancer Education Sites

#### America Lung Association

800-548-8252

This national association is dedicated to saving lives by improving lung health and preventing lung disease through research, education, and advocacy. The American Lung Association (ALA) offers multiple programs on tobacco cessation and improving environmental health. ALA also provides research grants and sponsors the education of medical professionals who plan to specialize in lung cancer research. Ala works to encourage the creation and enforcement of regulations and laws relating to lung health at national, state, and local levels.

# <u>American Melanoma Foundation</u>

858-882-7712

The American Melanoma Foundation (AMF) was founded by melanoma patients and their relatives with the mission of supporting research for new treatment approaches. The Website offers facts about melanoma; information on prevention, diagnosis, and treatment; and a clinical trials resource center. AMF also has several patient stories hosted at the website, and visitors are welcome to submit their own stories about living with melanoma. The site sponsors activities and events designed to raise awareness of melanoma and raise funds for melanoma research.

#### American Society of Hematology

This site offers information for understanding, diagnosis, treatment and preventions of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training and advocacy in hematology.

#### **Breast Cancer Action**

#### 877-278-6722

Breast Cancer Action (BCA) is a grassroots organization comprised of breast cancer survivors and their supporters. BCA educates the public on breast cancer issues by providing downloadable flyers and fact sheets on breast cancer issues. BCA also advocates for policy changes that are likely to help reduce the incidence of breast cancer and reduce disparities in breast cancer outcomes.

# Colon Cancer Alliance

877-422-2030

Colon Cancer Alliance (CCA) was founded in 1999 to provide support for those with this disease. The organization has several local chapters throughout the Unites States and Canada. CCA works with other advocacy groups to increase effective treatments or a cure for colorectal cancers. CCA provides patient support and a variety of disease management services. The Website includes downloadable fact sheets on diagnosis and treatment.

#### Dr. Susan Love Foundation for Breast Cancer Research

This site concentrates on pursuing research programs and promotes breast disease education.

# **Esophageal Cancer Awareness Association**

800-601-0613

The Esophageal Cancer Awareness Association (ECAA) is relatively new organization that seeks to provided information and support for individuals with esophageal cancer and their families and caregivers. ECAA raises money for research into the causes, treatments, and outcomes of esophageal cancer. The Website provides easy to read information on esophageal cancer, such as descriptions of the disease, how it is diagnosed, staging, treatment options, and risk factors. ECAA also publishes a quarterly newsletter outlining its advocacy efforts and new research.

# **GIST Support International**

215-340-9374

GIST Support International (GSI) provides education and support for individuals and their families who are affected by a diagnosis of gastrointestinal stromal tumor (GIST). The Website has information on clinical trials, a section that provides the latest research news and advice for patients who have received a recent diagnosis. Visitors can access English and Spanish downloadable brochures in the learning center or under educational materials. There is an extensive section on treatment options, and a list of common questions and answers about GIST.

# <u>Gynecologic Cancer Foundation: National HPV & Cervical Cancer Campaign</u> 312-578-1439

The Gynecological Cancer Foundation has launched a nationwide campaign designed to educate women and physicians on the causes of cervical cancer and the best way to prevent or detect the disease. There is a wealth of patient resources, including facts on the human papillomavirus (HPV) and vaccination. The site includes a physician search engine and an "Ask a Doc" section with common questions and answers.

#### International Myeloma Foundation

800-452-2873

The international myeloma Foundation (IMF) compiles up-to-date information on the latest in myeloma research. The organization offers several publications and Webcasts designed to educate patients, families, caregivers, and the medical and scientific communities on multiple myeloma. IMF also guides patients on obtaining legal help or getting assistance for reimbursement issue. Patients can also find information on clinical trials and support services at the website.

#### **Kidney Cancer Association**

800-850-9132

The stated mission of the Kidney Cancer Association (KCA) is to fund, promote, and collaborate with other institutions on research projects; educate physicians and patients about kidney cancer and its treatment; and advocate at federal and state levels on behalf of patient interests. The Website features newsletters and Podcasts, as well as an abundance of information on the disease. Visitors can ask a question online or contact a nurse through the KCA- sponsored nurse hotline at (503) 215-7921.

#### **Living Beyond Breast Cancer**

888-753-5222

Living Beyond Breast Cancer (LBBC) provides education and advocacy services to patients and families affected by breast cancer. LBBC offers a toll-free helpline for breast cancer survivors and distributes a free quarterly newsletter. The site also provides information on breast cancer specific to the unique concerns of African American and Latina women. LBBC seeks to extend the lifespan of patients with breast cancer and improve their quality of life.

#### Lung Cancer Alliance

800-298-2436

Eradicating lung cancer is what the nonprofit Lung Cancer Alliance (LCA) is all about. This national organization is dedicated solely to providing patient support and advocacy for people living with or at risk for the disease. Recognizing that clinical trial participation is the best way to make progress against lung cancer, LCA sponsors a clinical trial matching service for patients.

#### **National Brain Tumor Society**

800-770-8287

The National Brain Tumor Society (NBTS) serves as a resource center for patient, families, caregivers, researchers, and medical professionals. The Website is available in English and Spanish and features information on several types of brain tumors and their treatments. NBTS offers a variety of patients support services including advice on how to get financial assistance. The fundraising efforts sponsored by NBTS help support research that is linked directly to patient care and enhances the quality of life for individuals with brain tumors.

#### National Cervical Cancer Coalition

800-685-5531

Through outreach and coordination with other organization, the National Cervical Cancer Coalition (NCCN) educates the public on the need for cervical cancer prevention and seeks to increase awareness and funding through its advocacy efforts. NCCN offers a hotline for women and family members battling issues related to cervical cancer and HPV. NCCN also sponsors CME conference credits for physicians.

#### National Comprehensive Cancer Network

This is a not-for-profit alliance of 21 of the world's leading cancer centers. They are dedicated to improving the quality of effectiveness of care provided to patients with cancer.

#### National Ovarian Coalition

214-273-4200

This organization provides the medical community and the general population with a comprehensive resource for ovarian cancer information. The National Ovarian Cancer Coalition works to raise awareness about the incidence, prevalence, and clinical presentations of ovarian cancer. The Website provides information on participating in clinical trials and operates a helpline at 888-OVARIAN.

#### **Oral Cancer Foundation**

949-646-8000

This national public service nonprofit entity works to reduce the suffering of people with oral cancer and save lives though prevention, education, research, advocacy, and support activities. The Oral Cancer Foundation (OCF) Website features a patient/survivor discussion forum, open to the public, where those currently fighting oral cancer can gain insight and inspiration from others who have been there. It also provides hundreds of pages of information on oral cancer and discusses facial reconstruction.

# People Living with Cancer

This is an award-winning patient website from ASCO. It provides accurate, comprehensive, oncologist-approved information to help people make informed health-care decisions.

# **Prostate Cancer Foundation**

800-757-2873

The Prostate Cancer Foundation (PCF) is an international organization that helps fund clinical research in the quest to find a cure for prostate cancer and improve treatment. PCF produces guides for patients on how to discuss prostate cancer, what to expect from treatment, and how to live with prostate cancer. The organization also distributes a newsletter on advances in prostate cancer research. The Website has a wealth of information on the disease and discusses the organization's research efforts and grant offerings.

#### Susan E. Lusty Glioblastoma Foundation

908-637-6039

A main focus of the Susan E. Lusty Glioblastoma Foundation (SELF) is to help patients undergoing treatment at Memorial Sloan-Kettering Cancer Center in New York City with nonmedical expenses. SELF helps arrange accommodations close to the treatment facility for patients, family members, or friends and provides transportation. The Website hosts a variety of resources, including a downloadable brochure offering support and information to patients with glioblastoma. SELF provides several links to resources available online at various institutes famed for cancer research and treatment. In addition, patients can communicate with other patients via the SELF message boards.

#### Susan G. Komen®

877-465-6636

This well-known US- based organization funds research grants and supports breast cancer education, screening, and treatment projects throughout the world. At the Susan G. Komen Website, visitors can access information about all aspects of breast health. They can also download educational materials and get information about community support groups.

#### The American Cancer Society

Invaluable site that offers information on clinical trails and drugs used to treat cancer. One of the most reliable sources for you.

#### The American Society of Clinical Oncology (ASCO)

ASCO is the world's leading organization representing physicians of all oncology subspecialties who care for people with cancer. ASCO guidelines in addition to NCCN guidelines are what most oncologists use to guide their treatment.

#### The Leukemia and Lymphoma Society

They are the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services.

# The Myelodysplastic Syndrome Foundation

800-637-0839

The myelodysplastic Syndromes Foundation (MSF) is an international organization established by physicians and researches to foster the exchange of information on myelodysplastic syndromes (MDS). MSF helps refer patients to top-notch treatment centers and provides them with contact information for ongoing clinical trials. MSF has established patient advocacy groups, research funding, and physician education. The Website includes a link to online forums where patients and caregivers can discuss living with MDS.

# The National Cancer Institute

This is a US government agency responsible for conducting and supporting research on cancer. This site offers complementary and Alternative Medicine information on cancer treatment types, open clinical trials and supportive care.

#### The Prostate Net

888-477-6763

Prostate Networks to provide information to men at risk for prostate cancer or dealing with a diagnosis of prostate cancer. Through several programs and outreach efforts, Prostate Net also seeks to eliminate disparity in prostate cancer care. The site features information on treatment options, a physician referral service, Podcasts, and a telephone hotline for those who need one-on-one support.

# Online Support Groups:

#### **Cancer Together**

They are about giving a face and a voice to the stories and experiences of people affected by cancer. Offers those who are living or have lived with cancer an opportunity to share their hard-earned wisdom and insight. They offer educational and inspirational videos on their website.

#### Financial Assistance:

We understand the financial burdens that can impact healthcare. We have a billing team, and a team of financial assistants that are highly caring and will do their best to help you with patient co-pays and coinsurances. Patients must meet certain guidelines in order to qualify, but we assist in making the application process much smoother. If you would like more information, please contact us at any time regarding financial assistance and we'll be happy to assist you.

Social Security and SSI

800-772-1213

New Mexico Human Services Department

Medical Assistance Division:

https://www.hsd.state.nm.us/Medical Assistance Division.aspx

Customer Service Hot Line: 1-888-997-2583

Cancer Care

800-813-HOPE

This is a national non-profit organization whose mission is to provide free professional help to anyone affected by cancer through counseling, education, information and referral and direct financial assistance.

# Credit Card Counseling Centers of America

800-493-2222

Nonprofit organization that helps with financial information.

# <u>Patient Advocate Foundation</u>

800-532-5274

Insurance and Financial Information

In-Home Support Services

888-944-4477

Helps pay for services to eligible persons to enable them to stay at home.

#### The Center for Medicare Advocacy, Inc.

Insurance, financial information, advocacy, publications, scholarships for survivors.

# Transportation and Travel Assistance

The National Patient Travel Line

800-296-1217

Resource Center that provides referral and information mainly for air transportation and limited ground transportation.

Ver. 1.0