



**COLLEGE STATION** 

Dear Patient,

#### **Cancer hates fighters**

We say this because it's more than just a phrase. We say this because it's who we are. We say this because you are not alone.

We are here for you, with an experienced and compassionate team of physicians, nurses, medical assistants, social services and clerical staff that's on your side. They are here to encourage, support and empower you throughout the process.

This booklet is here to help you organize the personalized materials about your treatment, appointments and medications; and to provide information about our programs and resources.

Please bring it to your appointments and feel free to ask questions as you play an active role in your journey.

Thank you for choosing us for your care. We are grateful for the opportunity to serve you and are committed to never settle as we address your needs and place you at the center of all we do.

On your side, always, Your Oncology Care Team



# My to-do's

| ■ Read through this and bring it to future visits.   |
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| ☐ Get a full explanation of my diagnosis and plan of recovery.   |
| □ Share what is most important with my doctor, so goals can be included in my treatment plan.  |
| □ Record appointments and reminders on the calendar.   |
| ■ Use the sections under the "at every visit" tab to track medications, side effects of chemotherapy, radiation therapy and lymphedema (if applicable). Please have a family member, friend or caregiver help keep these up to date. |
| ☐ Sign up online for MyBSWHealth, where I can view appointments, portions of my medical records and test results; make and cancel appointments; message my physician and more.   |
| □ Discuss fertility options before treatment, if wanting children in the future.   |
| □ Ask for support or counseling for emotional, sexual or relationship issues.  |
| □ Discuss financial concerns with the care team, if financial concerns may make it hard to follow the treatment plan.  |

# Your supportive oncology team

Your care team at Baylor Scott & White Cancer Center is here to provide practical, emotional and spiritual support as you and your family go from diagnosis through treatment and beyond. We're dedicated to listening and responding to your concerns, treating each patient with respect and compassion and helping you take an active role in managing your health. Feel free to schedule an appointment with any member. These services are available to patients and their families at no additional cost.\*

#### **Nurse navigator**

Your nurse navigator is here to provide comfort by connecting you with information on diagnosis and treatment options. Their goal is to offer assistance to overcome healthcare system barriers, facilitate timely access to quality care and point you in the right direction.

#### Financial counselor

Your financial counselor provides timely verification of insurance benefits and treatment clearance while coordinating information between the insurance company and clinical team. She is also available to help with eliminating or easing insurance barriers that may lead to a delay in treatment for patients.

#### Social worker

We are in it together, and you have access to a variety of desired support services. Your social worker will assess your and your family's psychosocial needs, and connect you to education regarding advance directives, home health and hospice care, family leave and disability benefits, transportation and cancer-related support programs.

#### **Psychotherapist**

A cancer diagnosis presents new challenges and comes with a range of feelings. Finding healthy ways to cope can positively affect your course of treatment and improve quality of life during what can be a very stressful time. Your psychotherapist is available to provide individual counseling, addressing common concerns like coping and adjusting to cancer diagnosis, self-image, depression, anxiety, grief and loss. If you are interested in these services, please discuss with your oncologist and a referral can be placed for you.\*

#### **Dietitian**

Healthy eating is important for everyone, especially for patients with cancer diagnoses. Your licensed dietitian is available to provide up-to-date research-based education, assessment and counseling. They also work alongside your healthcare team to identify opportunities for nutritional intervention or support.

#### Pastoral care

Just as the medical staff provides treatment to the body, pastoral care provides treatment for the soul. Spiritual care can bring comfort, well-being and meaning in times of stress and illness with interfaith spiritual support for you and your family. A chaplain is available to offer support to complement the healing process.

#### 979.207.4100

Baylor Scott & White Medical Center - College Station

<sup>\*</sup>Counseling services will be charged as per your insurance.

# Important phone numbers -

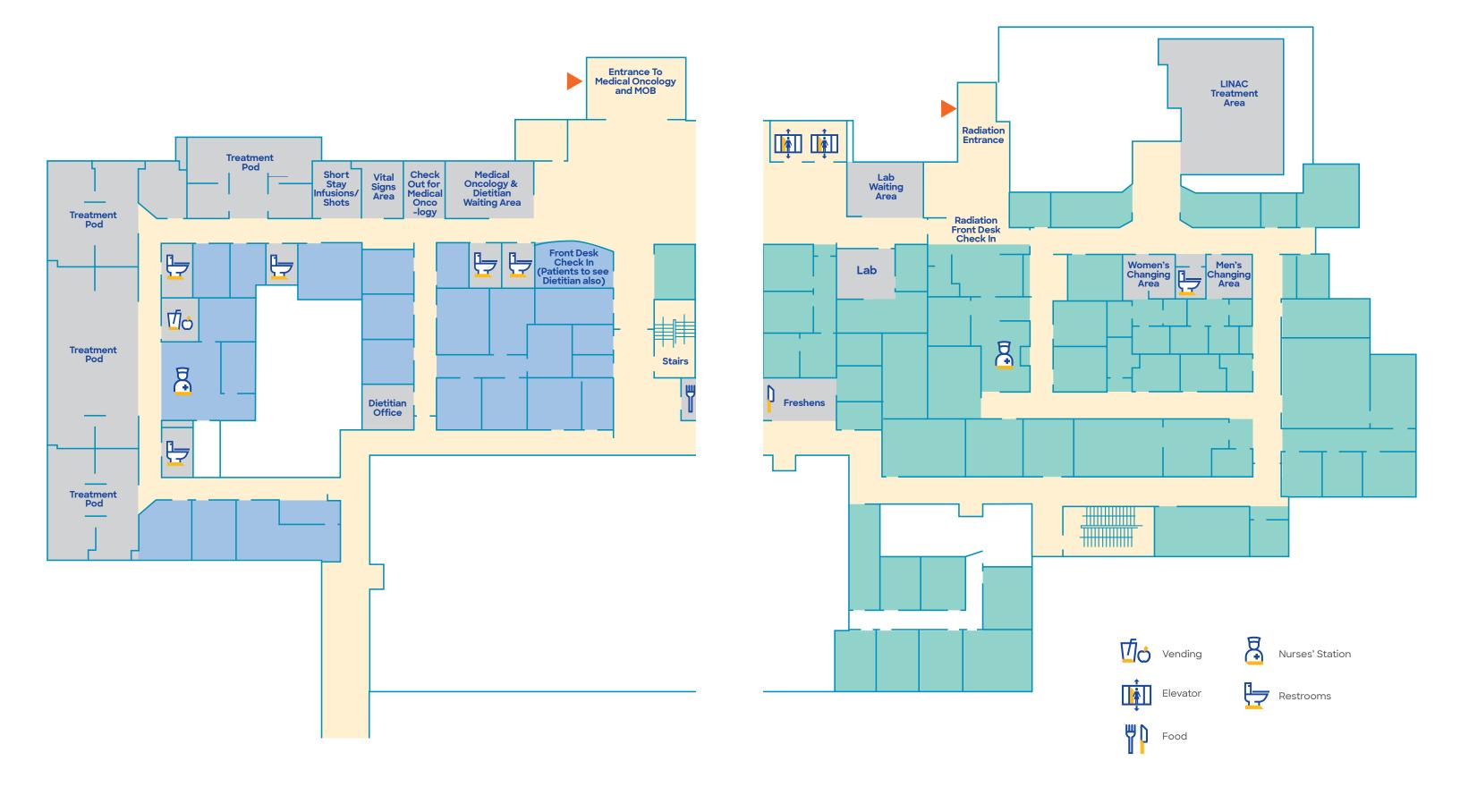
Fill in the names and phone numbers below. Office hours: Monday - Friday, 8:00 AM - 5:00 PM Medical oncologist: Radiation oncologist: **Nurse practitioner:** Social worker: After hours/weekends/holidays:

# Medication list -

Please list all prescriptions, vitamins, herbs and over-the-counter medications that you are currently taking. You can also bring your medications to your appointment.

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# **▼** Cancer center 1st floor



# **▼** Helpful items to have at home

**Thermometer** >>> To take temperature regularly

**Antihistamine (Benadryl)** For hypersensitivity/allergic reactions

**Biotene Products** >>> To help with dry mouth symptoms

Mints >>> To help with metallic taste and nausea

Ginger candy/chews >>> To help with nausea and dry mouth

**MiraLAX** >>> To help with constipation (one side effect of Zofran is constipation)

**Journal** >>> To maintain a log of symptoms

**Electric razor** >>> To minimize bleeding

**Soft toothbrush** >>> To help prevent mouth sores & minimize bleeding

Lip moisturizer

**Hand sanitizer** >>> To prevent the spread of germs

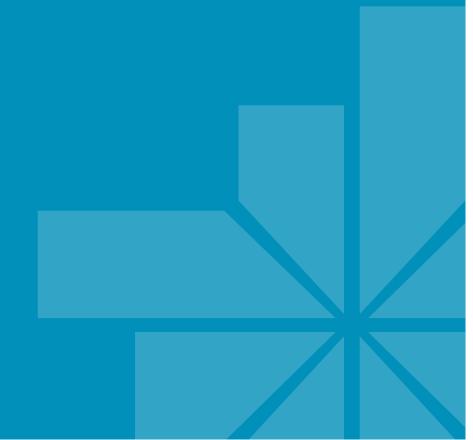
Moisturizer–NO alcohol, dyes or fragrance >>> e.g., Phytoplex, Miaderm, Aquaphor, Calendula Cream or Gel, Aveeno Intense Relief Lotion, Aveeno Skin Relief Lotion, Lubriderm Sensitive Skin Therapy, 100% Aloe Vera

Hat/Scarf/Beanie/Wig >>> To protect head from sun and cold

**Condoms** >>> To prevent sharing chemotherapy with your partner

**Birth Control** >>> To prevent pregnancy during chemotherapy

# CALENDAR







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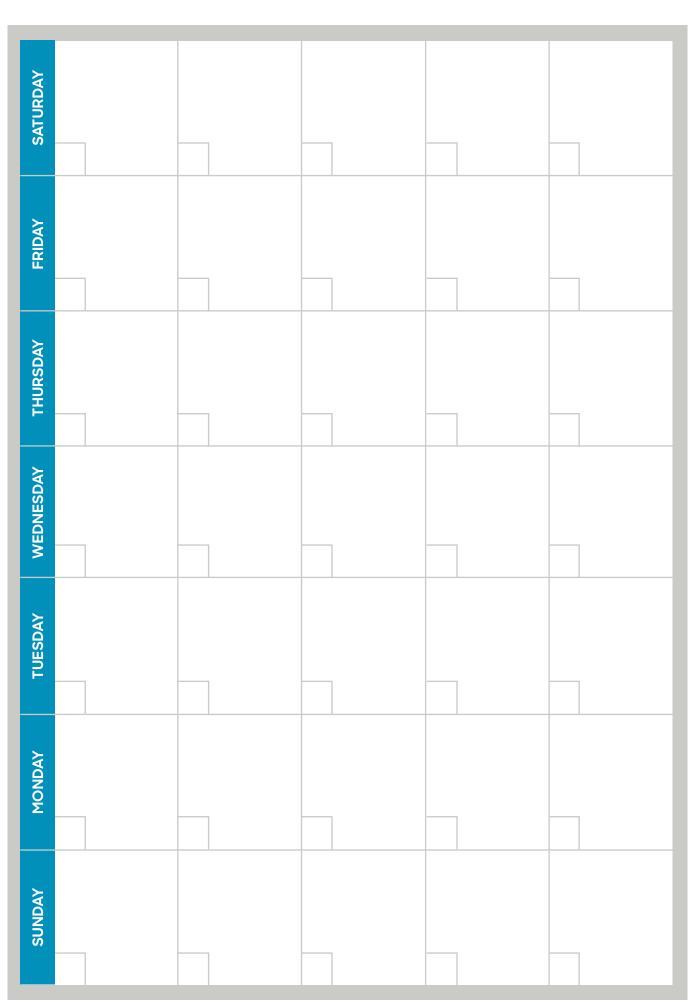


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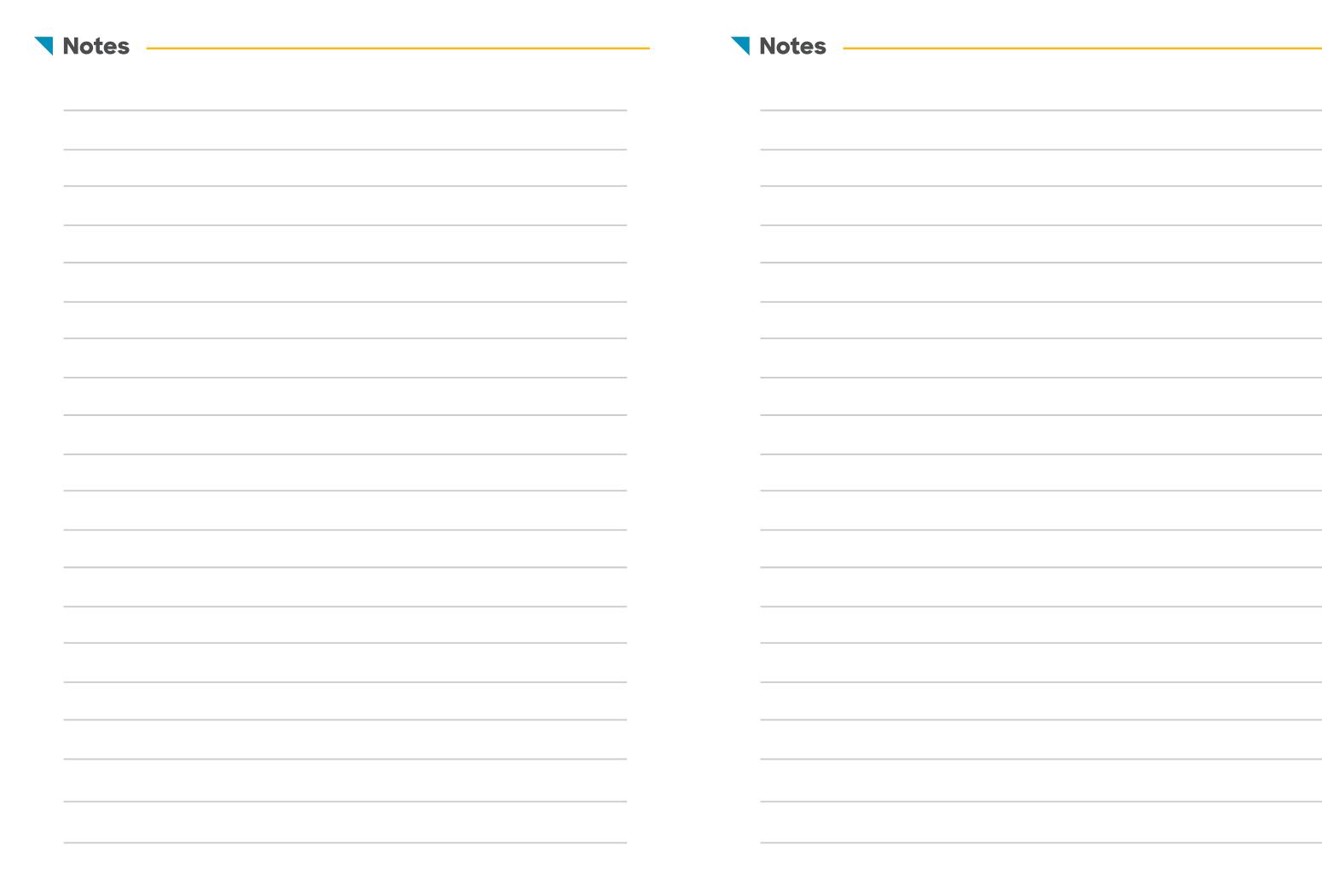
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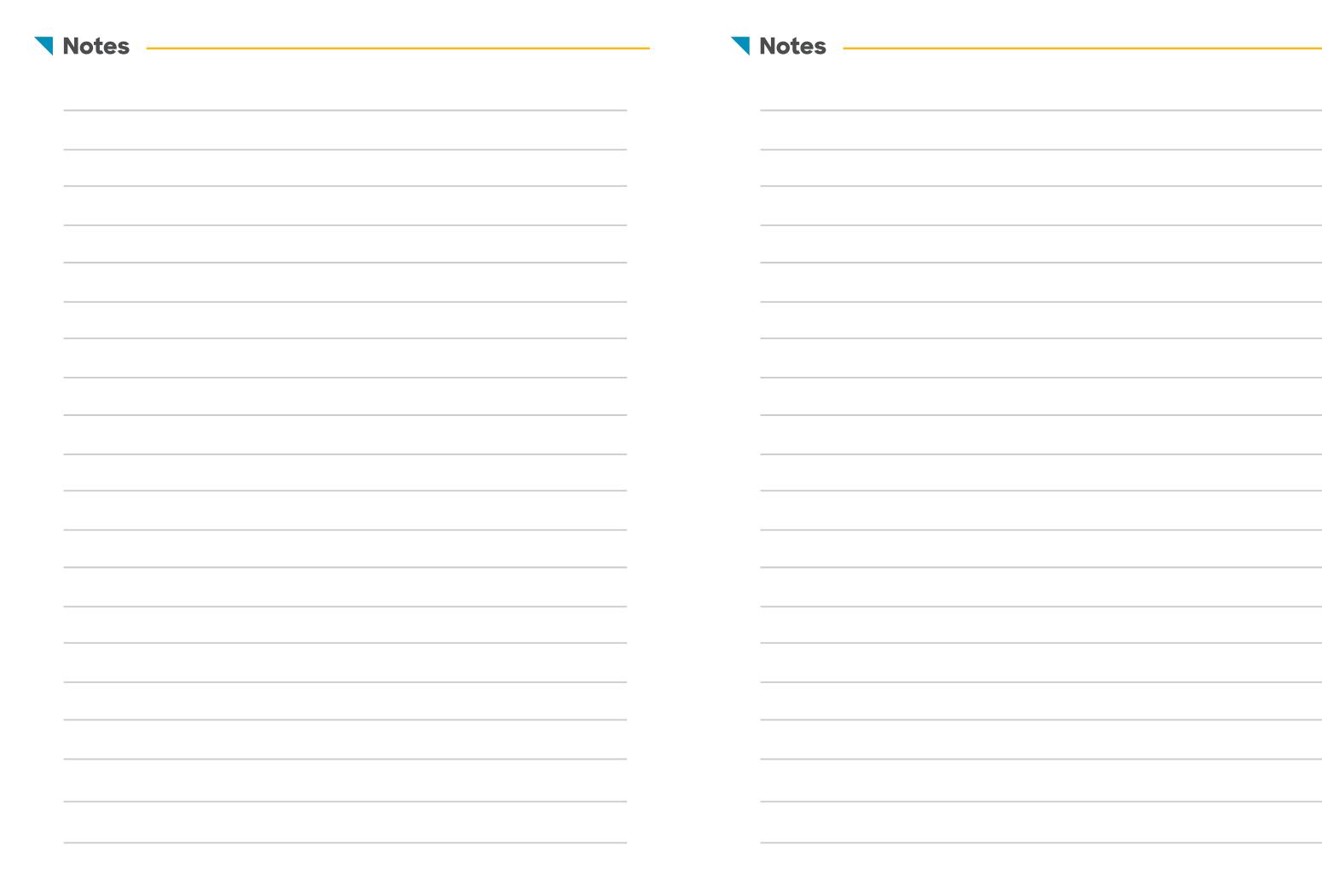
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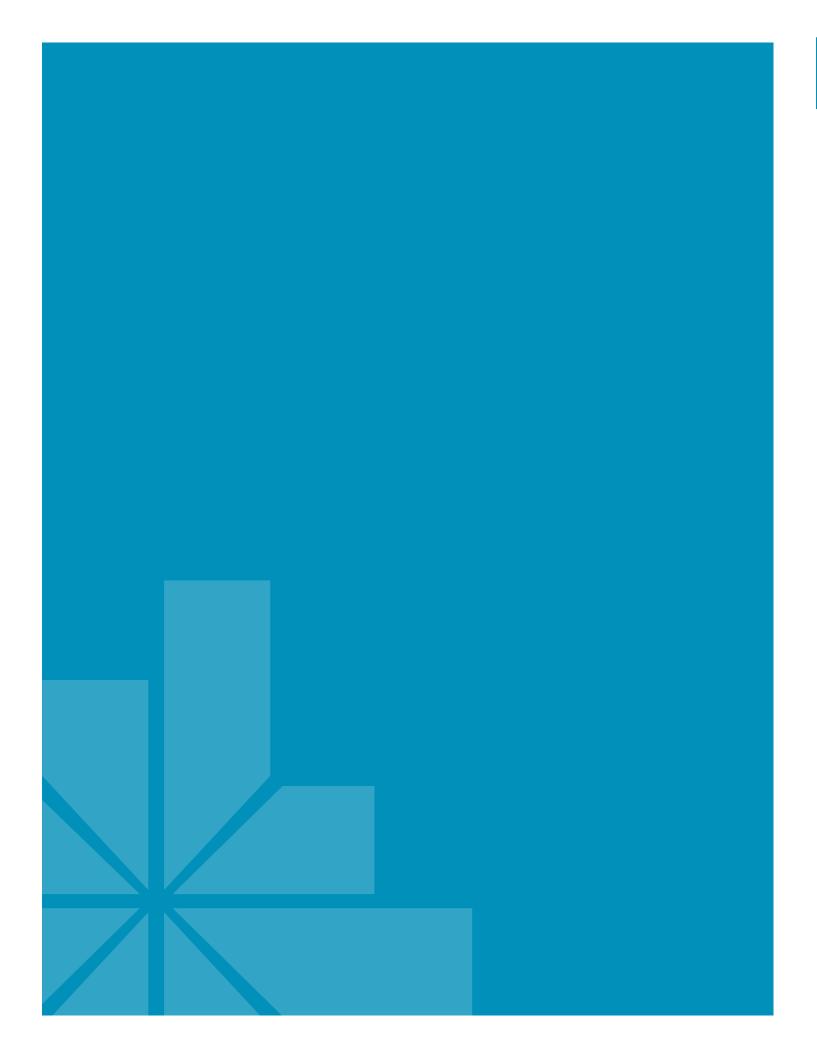




# **▼** Questions for my doctor

| Use this section to write down questions, so you'll remember to ask your healthcare tear |
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# RESOURCES AND SUPPORT



# Measuring swelling due to lymphedema



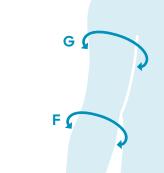
Lymphedema is a painful swelling that is a common side effect of cancer treatment. This happens when your body is unable to circulate fluids properly. It's important to routinely measure and accurately track this swelling using the chart below. Lymphedema should be treated early to prevent permanent damage.

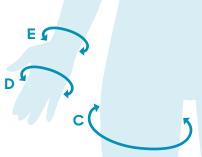
- **A** Ankle
- **B** Calf
- **C** Thigh
- **D** Palm measure at knuckles
- **E** Wrist measure at smallest part
- F Forearm measure at largest part
- **G** Upperarm measure at largest part

#### **General guidelines**

- Measure first thing in the morning for the most accurate measurements.
- ▼ Limbs should be measured next to bare skin.
- The measuring system is based on the angle between the sole of the foot and leg or arm being at 90,° for best results.
- Measurements must be taken by pulling the tape snugly around the leg but without constriction.
- Measurements should be taken from the ground up.

Baseline measurements should be taken prior to surgery. Take another measurement if you begin to feel swelling in your arm/leg. If this swelling does not go away within a week, notify your doctor.









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# **National resources**



#### **American Cancer Society**

Trusted information about all cancer types, cancer treatments and support, including the "look good feel better" program.

800.227.2345 | cancer.org | lookgoodfeelbetter.org

#### **Cancer Support Community**

An international nonprofit organization that provides support, education and hope to people affected by cancer.

202.659.9709 | toll-free 888.793.WELL | cancersupportcommunity.org

#### Cancer.net

Information from the American Society of Clinical Oncology on cancer types, treatments, advocacy and survivorship.

Cancer.net

#### CaringBridge®

An online space where patients and families can share cancer stories, connect, provide updates and receive support.

651.789.2300 | CaringBridge.org

#### The Leukemia & Lymphoma Society

The world's largest voluntary health organization dedicated to funding blood cancer research and providing education and patient services.

Toll-free 800.955.4572 | LLS.org | email: infocenter@LLS.org

#### **National Cancer Institute**

Part of the National Institutes of Health. Cancer information, resources, clinical trials. Live chat on website.

Toll-free 800.422.6237 | cancer.gov

#### **Needymeds**

Free information on programs that help people who can't afford medications and healthcare costs.

Toll-free 800.503.6897 | needymeds.org

#### **Partnership for Prescription Assistance**

Support for qualified patients without prescription drug coverage.

Get medicines for free or nearly free.

Toll-free 888.4PPA.NOW (888.477.2669) | pparx.org

#### **Patient Advocate Foundation**

Assists with insurance and access to healthcare.

757.873.6668 | toll-free 800.532.5274 | patientadvocate.org

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# **Support groups**



#### Bladder cancer

Bladder cancer advocacy network online support group

1.888.901.2226 https://bcan.org

#### **Breast cancer**

#### Pink alliance

The Travis B. Bryan, Jr. Community Room
The Bank & Trust | 2900 S. Texas Avenue | Bryan, TX 77802

Patricia Gerling 979.224.3813 | Linda Cerami 979.690.2592 PinkAllianceGroup@gmail.com

In-person support group 2nd & 4th Tuesday of each month 6:30 PM - 8:00 PM

#### Reach to Recovery-American Cancer Society

In-person, phone or online 800.227.2345

#### Cancercare.org online support group

cancercare.org/support\_groups

#### **Colorectal cancer**

#### Cancercare.org online support group

cancercare.org/support\_groups

#### **Gynecological cancers**

#### **National Cervical Cancer Coalition**

P.O. Box 13827 Research Triangle Park, NC 27709

Local: 818.992.4242 Toll-free: 1.800.685.5531 (responds to calls in English only)

nccc-online.org/

#### Head and neck cancers

Head and Neck Cancer Alliance (HNCA) online support group HeadAndNeck.org/support-community

#### Support for People with Oral and Head and Neck Cancer

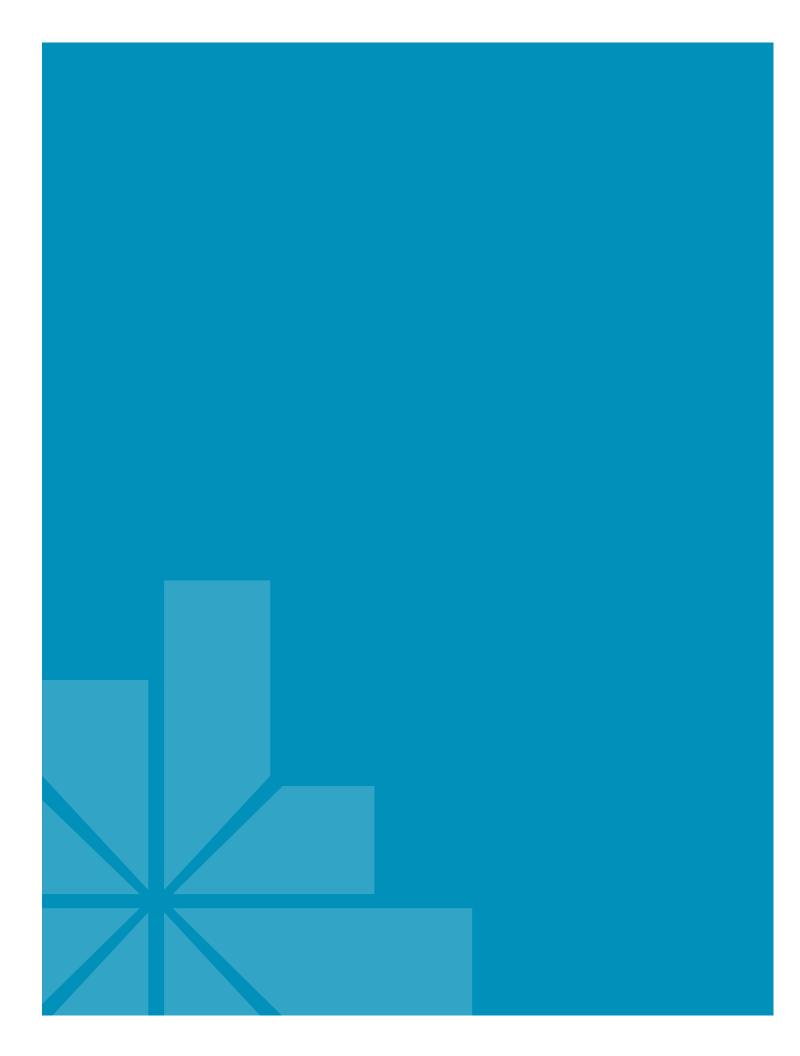
P.O. Box 53 Locust Valley, NY 11560 Toll-free: 1.800.377.0928

#### **Thyroid Head & Neck Cancer Foundation**

THANCFoundation.org

#### **Lung cancers**

American Lung Association online support group 1.800.586.4872 (1.800.LUNG.USA) lung.org CHEMO THERAPY



# What to expect from chemotherapy



#### **Before chemotherapy**

- You may eat before coming for your chemotherapy. Many people find it helpful to eat a light breakfast or lunch.
- A non-fasting blood test will be done the day before chemotherapy is ordered.
- Write down any questions on side effects that you may have and bring them with you to discuss with your doctor or nurse.
- Bring someone to drive you home from your first treatment.

#### **During chemotherapy**

- Wear comfortable clothing and bring a sweater.
- Bring your favorite blanket/pillow.
- You may bring books, games, tablets, laptops, etc. As a courtesy to others, we ask that you bring earbuds or headphones.
- Please try to limit phone calls; we want to keep the infusion area as "calm" as possible for everyone.

#### **After chemotherapy**

- Before you leave, a return appointment will be made. Make sure you check out at the appointment desk to schedule your next appointment (if you do not already have one).
- You may eat after chemotherapy. Try light meals.
- The bandage over your IV site can be taken off in about one hour.
- Avoid beer or alcohol after chemotherapy.
- You can return to your usual activities unless otherwise instructed.
- Let your body be your guide. Do not overdo it.
- ▼ Sexual activity is OK after chemotherapy—use condoms.

#### After chemotherapy continued

- ▼ For the 48 hours after chemotherapy:
  - ▼ Flush toilets twice after using the bathroom.
  - Use gloves to clean up vomit, diarrhea or urine.
  - If bedsheets or clothing gets soiled with vomit, diarrhea or urine, wash separately from other clothes.
  - Diarrhea is a potential side effect of many chemotherapy agents. You may take Imodium A-D as directed.
  - Please take nausea medications as instructed. You may also take MiraLAX if needed to relieve constipation caused by nausea medications.

#### Other hints:

- It is important to keep appointments and stay on your regimen cycle if able, yet we understand that things may come up. Please communicate with us, so that we can ensure you receive the best care possible.
- ▼ Please ask questions, if you have them.
- Neep your nausea medications on hand.

# SIDEEFFECTS

- Anemia
- **▼** Chemo brain
- Constipation
- **▼** Fatigue
- **▼ Decrease in platelets** (thrombocytopenia)
- Diarrhea
- **▼** Hair loss
- Infertility
- **Insomnia**
- Lymphedema
- **▼** Mouth care
- Nausea & vomiting
- Neuropathy (nerve damage)
- Neutropenia (low white blood count)



# Anemia



#### What is it?

Red blood cells carry oxygen and nutrients throughout the body. A complete blood count (CBC) is a blood test used to check your blood count. When there are too few red blood cells, your body does not get enough oxygen to do its work. This is called anemia. The RBC, hemoglobin and hematocrit are tests to see if you have a low red blood count.

- Chemotherapy or radiation therapy can reduce the body's ability
  to make red blood cells, which carry oxygen to all parts of your body.
- Anemia can make you feel very weak and tired. You may also feel dizzy, have chills, shortness of breath or increased heart rate.
- Your doctor will check your red blood cell count often during your treatments. If your red blood count falls too low, you may need a blood transfusion.

#### What can you do?

- Rest between activities. Let your body be your guide.
- Plan ahead and save your energy for the most important activities.
- ▼ Get enough sleep consistently.
- Ask others for help.
- Eat well. Include iron-rich foods such as green, leafy vegetables if you can tolerate them.

#### When to call us:

#### Notify your doctor if you have any of the following:

- Textreme weakness for more than 48 hours.
- Increased shortness of breath.
- Dizziness or lightheadedness.

# Chemo brain



#### What is it?

Chemo brain (cognitive dysfunction) refers to trouble remembering details, not being able to think clearly or having difficulty processing information. This can occur during treatment and sometimes long afterward. Although associated with chemotherapy, it has been linked to other treatments, stress and hormone depletion.

#### What can you do?

There is no "quick fix" for chemo brain. It is important to be creative and do things in your daily life that can help fight the symptoms:

- ▼ Keep a detailed calendar or planner. Use your phone to set alarms to remind you of important appointments.
- Use sticky notes and put them in places you will see them!
- Spend time in the evenings making a list of what needs to get done tomorrow.
- Keep a notepad in the kitchen for a shopping list. When you see something is low, add it right away.
- Avoid distractions by having important conversations in a quiet place.
- ▼ Know your limitations and ask for help. Don't take on tasks that will ask for too much.
- Try to keep a positive outlook and find some humor in your "chemo-brain" moments.

#### **Useful websites for more information:**

- ▼ Cancer.org >> chemo-brain
- **▼ Cancer.net >>** attention, thinking or memory problems
- ▼ Cancercare.org >> coping with chemo brain, keeping your memory sharp

# Constipation



#### What causes it?

- ▼ Some chemotherapy drugs.
- Nedications like codeine, morphine, Tylenol #3, MS Contin, Dilaudid or Zofran. ■
- Changes in your dietary habits or a decrease in fluid intake.
- Decrease in activity or spending more time in bed.

#### What can you do?

Look for any changes in your normal bowel pattern. Are you moving your bowels less often? Has the color changed? Are the stools harder?

#### To prevent or lessen constipation:

- Try to increase fluid intake to eight full cups per day. Try water, fruit juices, coffee, tea, ice cream, sherbet, soup, popsicles, gelatin and broth. Warm and hot fluids often work as well.
- Eat high fiber foods every day, including bran, whole wheat breads and cereals, raw or cooked vegetables and fresh or dried fruit.
- Exercise 20 30 minutes most days of the week, as tolerated, and if okay with your doctor.

#### To relieve constipation, try the following non-prescription medications:

- Laxatives like MiraLAX
- ▼ Stool softeners like Senna or Colace

#### When to call us:

- Pain in your stomach
- Fever of 100.4°F (38°C)
- Nausea and vomiting along with your constipation
- No bowel movement in three days, despite following recommendations

# **Fatigue**



#### What is it?

Fatigue is described as a feeling of exhaustion, feeling completely worn out, feeling that your body is "heavy" and difficult to move, or an inability to concentrate. It is one of the most common side effects reported by people receiving cancer treatments (surgery, chemotherapy, radiation therapy or other drug therapies).

#### What can you do?

- Texercise has consistently been shown to improve fatigue levels and quality of life.
- Start easy, perhaps with a walk around the block. Increase the time or distance you walk slowly over time. Having someone to exercise with can help motivate and make it more enjoyable.
- Allow yourself to rest, but do not overdo it. Too much rest can make fatigue worse. Naps during the day should not be longer than 45 minutes to an hour.
- ▼ Conserve energy for when you need or want it most. Eliminate unnecessary tasks.
- Poor nutrition can worsen fatigue. Carbohydrates and proteins provide the most energy. Avoid heavy, fatty meals, or try eating four or five smaller meals as opposed to three larger ones.
- If possible, add complementary therapies, such as massage, relaxation techniques, meditation or yoga.

# Decrease in platelets (thrombocytopenia)



#### What is it?

Platelets help your blood to clot. They are found in the blood flowing through the blood vessels. Platelets also line the inside of the blood vessel. Thrombocytopenia is the term used when your platelet level is low. Radiation therapy, some chemotherapy medications and some cancers themselves can damage platelets and lead to thrombocytopenia. Patients receiving a combination of radiation therapy and chemotherapy are at higher risk for thrombocytopenia.

Because of the platelets' role in clotting, thrombocytopenia puts you at a higher risk of bleeding. Therefore, while you are receiving treatment, try to avoid any activities that could result in bleeding. Even the most minor of injuries, such as a small cut or bump, can result in too much bleeding when your platelets are low.

#### What can you do?

#### To prevent problems with bleeding:

- Use only an electric razor.
- Do not take aspirin or medicines containing aspirin.
- Prevent constipation.
- Use a soft-bristle toothbrush.
- Do not put yourself at risk for injury. Wear gloves when working in the garden. Wear shoes when outdoors. Avoid bumps, bruises and falls.

#### If active bleeding occurs:

- Apply direct pressure and elevate the area when possible.
- If bleeding does not stop after 10 minutes, call your doctor or nurse.

# Decrease in platelets (thrombocytopenia) continued

#### When to call us:

#### Notify your doctor or nurse if you have any of the following:

- Increased bruising, red or purple freckles under the skin. These often happen in the leg and ankle area.
- Nosebleeds that do not stop after 10 minutes.
- Mouth or gums that bleed easily.
- **▼** Pink or red urine.
- Bright red or black, tarry stools.
- If you are vomiting bright red blood or vomit that looks like dark coffee grounds.

# Diarrhea



#### What is it?

- Diarrhea (loose stool) is a side effect that may be caused by chemotherapy or radiation to the abdomen.
- Diarrhea can be mild or severe. If not treated, diarrhea can get worse and can even be life-threatening.

#### What can you do?

- Drink liquids at room temperature slowly. Avoid very hot or cold liquids.
- ▼ Let carbonated beverages like Coke® lose their fizz before you drink them.
- Drink 8 10 cups of liquid a day. A variety of fluids are best. Try clear liquids such as clear soup or broth, ginger ale, weak tea, 7UP or Gatorade.
- ▼ Frequently eat small amounts of soft, bland, low-fiber foods. Examples are bananas, rice, noodles, white bread, skinned chicken, turkey or mild white fish.

#### Should you develop diarrhea, take the following steps:

- Take two loperamide (Imodium A-D®) tablets following the loose bowel movement, then take one tablet after each diarrhea episode. Do not exceed six pills in 24 hours.
- Record the number of stools you have each day.
- Novid these foods:
  - Greasy, fatty or fried foods
- ▼ Rich pastries
- Raw vegetables or fruits
- Popcorn, potato chips and pretzels

- ▼ Strong spices
- Whole-grain breads and cereals, nuts, seeds and coconut
- Gas-forming foods and beverages like beans, cabbage and carbonated beverages
- Lactose-containing products (like milk and ice cream), supplements and alcohol.
- ▼ Limit foods and beverages with caffeine and beverages which are extremely hot or cold.

## Diarrhea continued

#### **Skincare:**

- Clean skin around the anus gently with warm water and a soft cloth, then dry gently and completely.
- Apply a barrier cream (such as Desitin®) to irritated skin.
- Allow the irritated skin to be exposed to open air as much as possible.

#### When to call us:

- Three or more watery stools over 24 hours
- Diarrhea that lasts for more than a 24-hour period
- ▼ Lightheadedness, dizziness or loss of more than three pounds in two days

If you have any questions about diarrhea and what to do about it, please call your doctor or nurse.

# **Hair loss**



Hair loss (alopecia) due to chemotherapy is one of the most distressing side effects of chemo treatments. While it does not occur with all chemotherapy, the extent of your experience will depend on your drugs and dosages.

#### Why does chemotherapy cause hair loss?

- Hair loss happens because chemotherapy affects all cells in the body, not just the cancer cells. The lining of the mouth and stomach and hair follicles are especially sensitive because those cells multiply rapidly just like the cancer cells. The difference is that the normal cells will repair themselves, making these side effects temporary.
- Hair loss may occur as early as the second or third week after the first cycle
  of chemotherapy.
- Hair loss can be sudden or slow, and you may lose all of it or just some.
- Often it comes out in clumps rather than an even pattern.
- It is not uncommon to have a mild sore sensation as the hair falls out.
- It is common for hair loss to include hair that grows anywhere including eyelashes, eyebrows and even pubic hair.

#### What can you do?

- You may find it helpful to get a wig or toupee. These may be a tax-deductible medical expense. Some insurance companies may cover the cost.
- We suggest that you get your hairpiece before you begin or at the start of chemotherapy. This will let you match your hairstyle and color. You will be prepared in case you lose your hair quickly.
- In cold weather, a large amount of body heat is lost through your scalp. Wear a hat, scarf, wig or other head covering.
- The scalp is sensitive to the sun. Protect against sunburn by keeping your head covered and by using a sunscreen of at least SPF 15.

## Hair loss continued

#### What can you do?

- Scalp care is important. Treat it gently. Washing your hair does not make it come out faster. Shampoo every two to four days to keep the scalp clean using a mild sulfate-free shampoo. Pat dry with soft towels. Washing your scalp every day may be too harsh. Avoid permanents, dyes, and using curling irons, curlers, hair bands, clips and hair sprays.
- If the scalp becomes dry, use aloe vera gel 97-100% pure.

#### Hair resources:

- Morgan Fitzgerald's
  3800 S. Texas Avenue
  Bryan, TX 77802
  979.268.0608
- Thair for you
  ThairForYou.org
  713.984.8800
- ▼ EBeauty wig exchange for gently used wigs\* ebeauty.com/
- Baylor Scott & White McClinton Boutique 150 Hillcrest Boulevard Waco, TX 76712 254.202.4035
- American Cancer Society
  2500 Fondren Road
  Suite 100
  Houston, TX 77063
  713.266.2877

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# Infertility



#### What is it?

Infertility can result from some cancer treatments for both men and women. Chemotherapy works by killing quickly dividing cells. This is the same for cancer cells or normal cells. Many cells in our bodies are quickly dividing, like those lining the gut, hair follicles and germ cells (including sperm and oocytes/eggs). This can affect the ability to become pregnant or maintain a pregnancy. If your plans include having a biological child, learn about fertility preservation with a reproductive specialist before treatment. Some preservation procedures may delay your cancer treatment, so discuss timing with your oncologist as soon as possible.

#### What can you do?

- Ask your physician for a referral to a specialist.
- Sperm banking: cryopreservation (freezing and storing) of sperm is the only proven method of fertility preservation for men.
- Egg or embryo cryopreservation is the collection and freezing of eggs or embryos for use at a later time. The collection process can take two to four weeks.

#### **Useful websites:**

- Livestrong.org >> Livestrong Fertility provides education and information to cancer patients regarding fertility risks, as well as referrals to access fertility preservation discounts.
- **YoungSurvival.org** >> Young Survival is an organization dedicated to helping women with cancer become mothers.
- Reprotech.com >> Reprotech offers support for embryo, semen, oocyte and ovarian tissue freezing and storage, as well as fertility preservation information.
- Oncofertility.Northwestern.edu >> The Oncofertility Consortium provides a telephone support hotline, education and clinic/center search options for people with cancer coping with infertility or potential loss of fertility due to cancer treatments.
- Resolve.org >> Resolve is the website of the National Infertility Association. They provide education, advocacy and information about fertility preservation as well as a database of support groups.

<sup>\*</sup>Will provide wig at no cost.

### Insomnia



Sleep problems are a common concern for patients with cancer. Insomnia can present itself in different ways, like waking up many times during the night, having trouble falling asleep, waking up early in the morning or being unable to fall back asleep.

#### What can you do?

- Maintain a regular bedtime and wake time every day.
- Tengage in regular physical activity in the morning and/or afternoon. Avoid moderate to strenuous physical activity within three hours of bedtime.
- Increase exposure to bright light during the day. Reduce exposure to bright light within a few hours before bedtime and during the night.
- Create a bedtime routine. This may involve reading, listening to relaxing music, drinking herbal teas, taking a warm bath or enjoying some guiet time.
- Avoid heavy meals and limit fluid intake within three hours of bedtime.
- Avoid alcohol and nicotine close to bedtime.
- ▼ Limit or avoid caffeine consumption at least four hours before bedtime.
- If necessary, limit yourself to one short nap per day in the afternoon, for no longer than 30 minutes.
- Turn off electronics and light-emitting sources at bedtime.

# Lymphedema



#### What is it?

Lymphedema is a painful swelling that occurs when your body is unable to circulate the flow of lymph through the lymph nodes. It may develop within days or many years after treatment, mostly developing within three years of surgery.

#### Risk factors for lymphedema include:

- Removal and/or radiation of lymph nodes in the underarm, groin, pelvis or neck.
  - Your risk of lymphedema increases with the number of lymph nodes affected.
  - There is less risk with the removal of only the sentinel lymph node (the first lymph node in a group of lymph nodes to receive lymphatic drainage from the primary tumor).
- Being overweight or obese.
- Slow healing of the skin after surgery.
- A tumor that affects or blocks the left lymph duct or lymph nodes or vessels in the neck, chest, underarm, pelvis or abdomen.
- Scar tissue in the lymph ducts under the collarbones, caused by surgery or radiation.

Lymphedema often occurs in breast cancer patients who've had all, or part, of their breast removed or have had axillary (underarm) lymph nodes removed. Lymphedema in the legs may occur after surgery for uterine cancer, prostate cancer, lymphoma or melanoma. It may also occur with vulvar cancer or ovarian cancer. Lymphedema occurs frequently in patients with cancers of the head and neck due to high-dose radiation therapy combined with surgery.

Possible signs of lymphedema include swelling of the arms or legs. However, other conditions may cause the same symptoms.

#### You should consult a doctor if any of the following problems occur:

- Swelling of an arm or leg, which may include fingers and toes
- A full or heavy feeling in an arm or leg.
- A tight feeling in the skin
- Trouble moving a joint in the arm or leg

# Lymphedema continued

- Thickening of the skin, with or without wearing clothing, shoes, bracelets, watches or rings
- Itching of the legs or toes
- A burning feeling in the legs
- Trouble sleeping
- ▼ Loss of hair

Lymphedema may affect your ability to enjoy daily activities, hobbies or work. These symptoms may occur very slowly over time or more quickly if there is an infection or injury to the arm or leg.

#### Managing lymphedema

There are steps you can take to prevent or lessen lymphedema.

#### Preventive steps include the following:

- ▼ Tell your healthcare provider right away if you notice symptoms of lymphedema
- ▼ Keep skin and nails clean and cared for, to prevent infection
- Avoid blocking the flow of fluids through the body
- Keep blood from pooling in the affected limb
- Carefully controlled exercise

Tell your healthcare provider right away if you notice symptoms of lymphedema. The chance of improving the condition is better if treatment begins early. Untreated lymphedema can lead to problems that cannot be reversed.

# Lymphedema continued

#### Preventive steps include the following:

- Using cream or lotion to keep the skin moist.
- ▼ Treating small cuts or breaks in the skin with an antibacterial ointment.
- Avoiding needle sticks of any type into the limb (arm or leg). This includes shots or blood tests.
- Using a thimble for sewing.
- Avoiding testing bath or cooking water using the limb with lymphedema.

  There may be less feeling (touch, temperature, pain) in the affected arm or leg, and skin might burn in water that is too hot.
- Wearing gloves when gardening and cooking.
- Wearing sunscreen and shoes when outdoors.
- Cutting toenails straight across. See a podiatrist (foot doctor) as needed to prevent ingrown nails and infections.
- Keeping feet clean and dry and wearing cotton socks.

#### Avoid blocking the flow of fluids through the body.

It is important to keep body fluids moving, especially through an affected limb or in areas where lymphedema may develop.

- No not cross legs while sitting.
- Change sitting position at least every 30 minutes.
- Wear only loose jewelry and clothes without tight bands or elastic.
- > Do not carry handbags on the arm with lymphedema.
- > Do not use a blood pressure cuff on the arm with lymphedema.
- > Do not use elastic bandages or stockings with tight bands.

# Lymphedema continued

#### Keep blood from pooling in the affected limb.

- Keep the limb with lymphedema raised higher than the heart when possible.
- > Do not swing the limb quickly in circles or let the limb hang down. This makes blood and fluid collect in the lower part of the arm or leg.
- Do not apply heat to the limb.
- ▼ Studies have shown that carefully controlled exercise is safe for patients with lymphedema. Speak with a certified lymphedema therapist before beginning exercise.

General guideline of high-risk, medium-risk and beneficial activities for upper and lower extremity lymphedema patients. Always take maximal precautions and discuss any planned activities you are unsure of with your lymphedema therapist.

# **High risk**

Gardening

Tennis/racquet sports

Golf

**Upper extremity** 

**Lower extremity** 

Shoveling snow

Moving furniture

Carrying luggage

Carrying grocery bags

Scrubbing

Weightlifting with arm

Intense horseback riding (gripping reigns)

## **Medium risk**

Jogging/running

Biking

(use aero-bars, minimize gripping)

StairMaster

(with aripping bars on the side)

NordicTrack (use minimum grip)

General weight lifting (of the rest of body)

Easy horseback riding (holding the reigns loose)

#### **Beneficial**

Swimmina

Lymphedema exercise program

Walking

Self-manual lymph drainage (MLD)

Yoga

Water aerobics

# **High risk**

Running

Intense biking

Moving furniture

Soccer

Hockey

Sitting/standing long periods

Weight lifting with legs

StairMaster (longer than 15 minutes)

Wrestling

Intense horseback riding

# **Medium risk**

Light jogging

Biking > 30 minutes

Skating > 20 minutes

Golfing

Weight lifting

Treadmill > 15 minutes

StairMaster > 5 minutes Volleyball or tennis

Easy horseback riding

## **Beneficial**

Walking

Easy biking 10 - 20 minutes

Lymphedema exercises

Easy skating 10 - 15 minutes

Swimming

Calf pumps

Treadmill 5 - 10 minutes

Deep-breathing exercises

Yoga

Water aerobics

# **Mouth care**



#### Create a routine:

It is important to take care of your mouth after meals and at bedtime.

#### Your routine should include:

- Brushing your teeth/dentures with a soft toothbrush at least twice a day/after each meal.
- Rinsing with salt and soda water. You can make this by adding 1 tablespoon salt and 1 tablespoon baking soda to 1 quart of water. It can be kept at room temperature for 24 hours. Do this rinse after each meal and at bedtime.
- Using mouthwash, avoiding any that contain alcohol.
- ▼ Keeping your lips moist to prevent cracking by using ChapStick, Vaseline or Blistex.
- Avoiding alcohol and cigarettes, which dry the lining of the mouth.
- ▼ Practicing good nutrition to heal mouth sores and help keep the mouth healthy.

#### What can you do?

#### Sore mouth

Mouth sores can be red, shiny, swollen areas, or they can be white spots/patches. The mouth may be tender, and bleeding can occur.

- A soft, bland diet may be more soothing to your mouth. Avoid hot, spicy and acidic foods.
- Thoose soft, soothing foods like ice cream, milkshakes, baby food, soft fruits like bananas and applesauce, mashed potatoes, cooked cereals, soft-boiled/scrambled eggs, cottage cheese, macaroni and cheese or custards/puddings/gelatin.
- You can also puree cooked foods in the blender to make them smoother and easier to eat.
- Your doctor can prescribe medicine to help relieve discomfort from mouth sores.

# Mouth care continued

#### Dry mouth

A dry mouth can be uncomfortable and make it hard for you to eat. You can alleviate the discomfort by:

- Drinking 8 10 cups of liquid a day.
- ▼ Sucking on ice chips, popsicles or sugarless hard candy.
- Chewing on sugarless gum.
- Dunking or soaking dry foods in liquids.
- Using extra butter, gravies, sauces, salad dressings, yogurt or mayonnaise to moisten foods.

#### Difficulty swallowing

The throat can get sore from chemotherapy or radiation. If you have pain when you chew and swallow, let your doctor or nurse know.

#### When to call us:

- Nouth sores or mouth soreness.
- Pain with eating or swallowing.
- ▼ Bleeding from mouth or gums.

# **Nausea & vomiting**



#### What causes it?

- Certain chemotherapy drugs.
- Radiation therapy over the stomach or esophagus area.
- ▼ Some strong pain medicines, as well as other prescriptions.

#### What can you do?

#### If you have problems with nausea and vomiting, try the following:

- Eating small amounts and snacking more often. Six small meals a day may be better than three large meals.
- Eating before you get too hungry.
- Avoiding heavy, high-fat and greasy meals right before chemotherapy.
- Eating bland foods like saltine crackers, toast or cereals when you first get up in the morning.
- ▼ Eating ice chips, hard candy or ginger chews to relieve nausea.
- Drinking eight full cups of fluid to prevent dehydration.
- Substituting white meats, such as turkey, chicken or fish instead of red meat, which is often difficult to tolerate.
- Not eating your favorite foods during this time. They will no longer be favorite foods if you begin to associate them with nausea and vomiting episodes.
- Taking your antiemetics (anti-nausea).

#### When to call us:

- When nausea and vomiting last for more than 48 hours.
- When nausea and vomiting are not relieved by taking medicines as directed.

# Neuropathy (nerve damage)



#### What is it?

Neuropathy is irritation or damage to the nerves. Nerves are long, wire-like fibers in your body that transmit information from one area to another. Peripheral neuropathy happens when a nerve or group of nerves has difficulty "communicating" with other nerves.

Since peripheral neuropathy may affect your mobility and ability to sense temperatures, it is important to take some simple precautions to ensure your safety.

#### What can you do?

- ▼ Wear gloves and warm socks, especially in winter.
- Always wear shoes both indoors and outside.
- If you have neuropathy in your hands, use knives, scissors, box cutters and other sharp objects with care.
- ▼ Protect your hands by wearing gloves when you clean, work outdoors or do any repairs.
- ▼ Keep your house well lit.
- Cover steps and your bathtub/shower with a non-skid surface.
- Use handrails.
- Tape down the edges of all throw rugs to avoid tripping.
- Test the temperature of the water with an area of your body that is not affected by neuropathy before any bathing and dishwashing.

# Neutropenia (low white blood count)



#### What is it?

The lowering of white blood cells (WBCs), which help you fight infections by destroying germs in your body, is called neutropenia. When your white blood cells are low from chemotherapy or radiation therapy, you may be more susceptible to an illness.

Your white blood cell counts will be carefully checked during your treatments. If the count is too low, your doctor may postpone or lower your dosage of chemotherapy.

#### What can you do?

#### You can decrease the chance of infection by:

- Washing hands often, especially after using the bathroom and before eating.
- Avoiding large crowds of people during the height of cold and flu season.
- Brushing your teeth and rinsing your mouth after meals and at bedtime.
- Getting immunizations. While they are typically recommended and encouraged, always check with your doctor first.
  - Keeping your bowels regular with diet and stool softeners, as prescribed.
  - Getting plenty of rest.

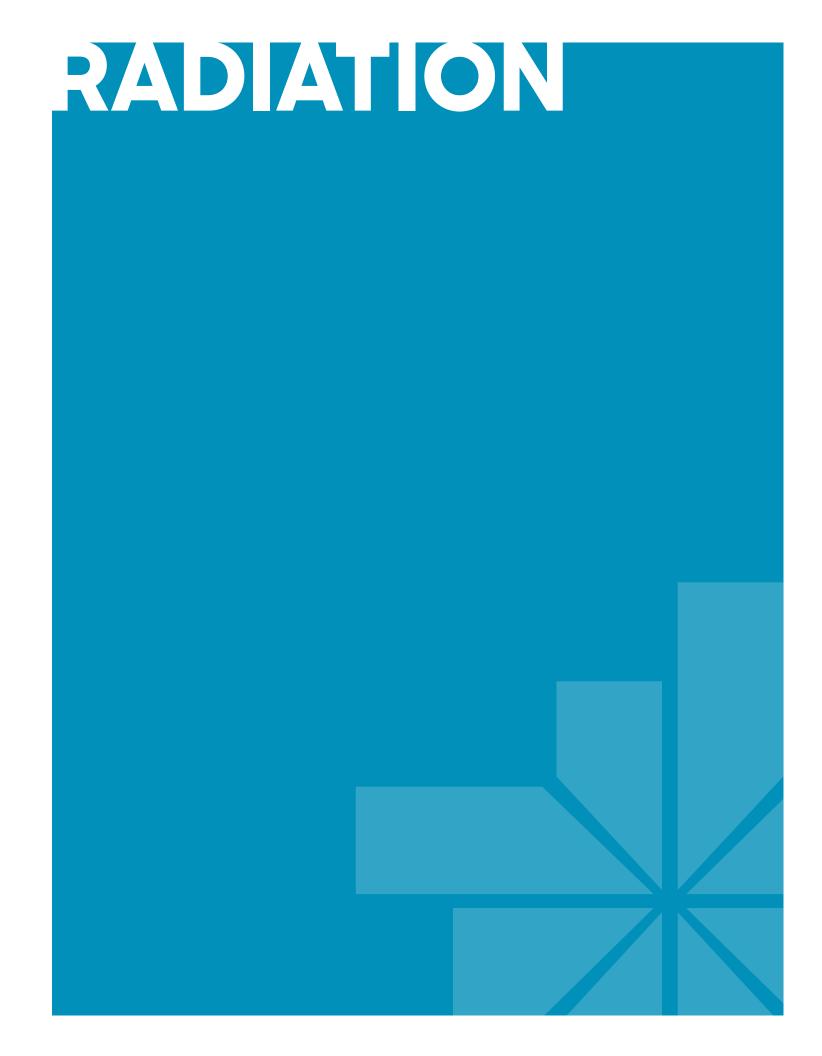
#### When to call us:

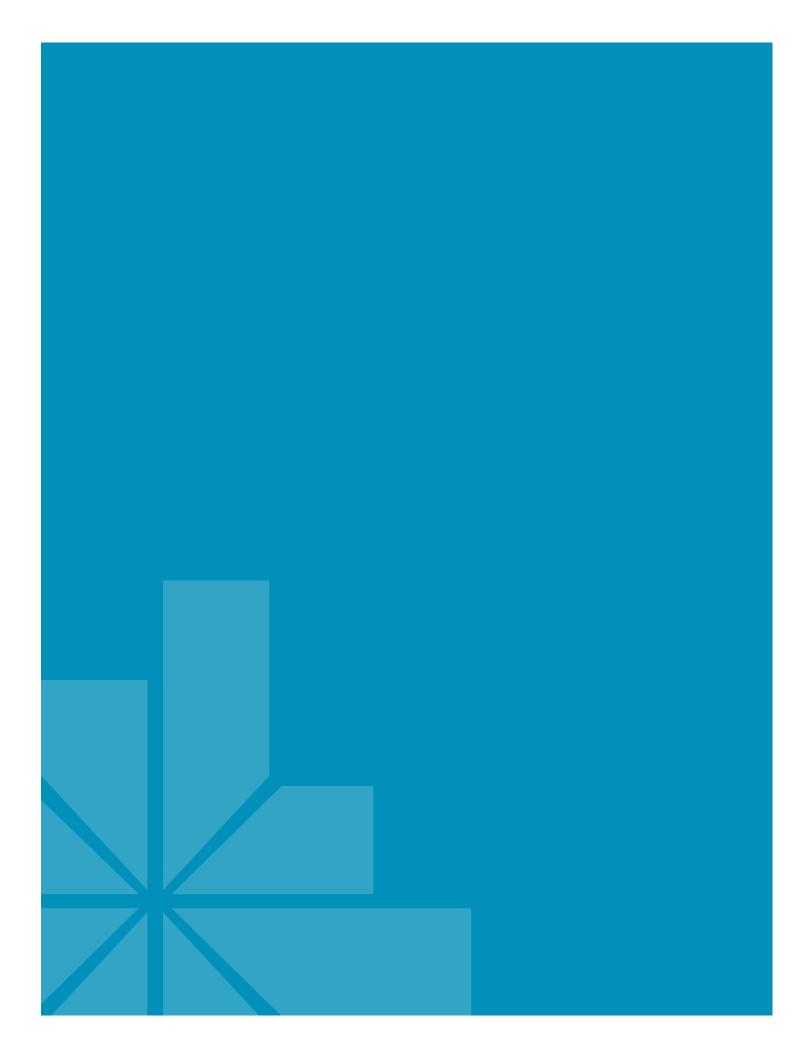
If your temperature is 100.4°F (38°C) or higher, notify your doctor right away, anytime day or night. Do not wait until the following morning to see if you are feeling better or if your temperature goes down.

# Neutropenia (low white blood count) continued

#### Notify your doctor if you have any of the following:

- ▼ Severe cough or sore throat
- ▼ Shaking chills
- Sweating, especially at night
- ▼ Diarrhea lasting more than two days
- ▼ Painful or burning urination
- Any area on your body that is red, painful or warm to the touch
- A wound or incision that has pus-like drainage or is not healing well





# What to expect



#### **During radiation:**

- Do not use bladed razors, hair-removal wax or creams on the treatment site. Before using an electric razor, check with your doctor. Some sites should not be shaved at all.
- Do not place deodorant, creams or lotions on the site, if being treated in the chest/breast area.
- Your doctor may have you use a special cream called Miaderm if there is significant dryness or irritation. This is the only cream you should use, and it should be applied after your treatment. Do not use at least four hours before your treatment.

After finishing treatment, you may notice skin reactions. This can take up to six weeks to heal.

#### Simulation

- Approximately one week before your treatment begins you will have an appointment for a simulation. The simulation is performed on a machine known as a simulator.
- This machine is a CT scanner but is used for radiation treatment planning.

  Depending upon the specific area of your body being treated, you may need to change into a gown.
- Upon entering the simulation room, you will be asked to lie down on the simulator table. Most patients are simulated lying flat on their back ("supine position"). However, it may be better for your treatment for you to be positioned face down ("prone position") Every effort will be made to find a position you can tolerate.
- Tell your radiation oncologist and simulator therapist(s) if you have any special physical limitations.

# What to expect continued

#### **Immobilization**

The next step in the simulation process is called immobilization. It is not possible for most people to remain motionless during treatment without assistance.

#### To reduce potential movements, various devices are used:

- Plastic mesh masks, called aquaplast masks, for the head and neck region are made from a hard plastic, which becomes flexible in warm water. When wet, they shape to your face and dry very quickly. Because it is mesh, you are able to breathe without difficulty.
- Blue Vac-Loc or bean bag devices are used to immobilize or hold you in the desired position. The device is deflated to conform to your body in the treatment position.

Making these various immobilization devices will take several minutes. You will be asked to lie still during this process, but you will experience no physical discomfort.

#### Marks Made on the Skin

You may require three or more small tattoos (mark with ink placed just under the skin) to help define the treatment field. They are permanent. They ensure proper alignment and reproducibility during your treatments. These tattoos are very small, approximately the size of a small freckle.

#### **Treatment Plan**

During the time between your simulation and your first treatment, the radiation oncology team will be working on your treatment plan.

#### Treatment planning involves several key steps:

▼ First, information and images from the CT simulation session are transferred to the treatment planning computers. Once there, dosimetrists work closely with your radiation oncologist and medical physicist to develop the best treatment plan—one that focuses on the area to be treated and avoids healthy tissues as much as possible.

# What to expect continued

■ Once your treatment plan is complete, you will be called by a radiation therapist to schedule your appointment time to begin your treatments. Many patients begin treatment approximately seven days after simulation; however, in patients requiring more complex treatment, additional planning may be necessary.

#### How long will my treatment take?

In general, you will be treated once a day, Monday through Friday, for 4 to 6 weeks. Some patients may have longer or shorter treatment courses. You will be given an appointment time for your daily treatment. This will be the time of your treatment for your entire treatment course.

#### **On-Treatment Visit (OTV)**

You will meet with your treating radiation oncologist once per week. This visit is called an on-treatment visit (OTV). This is a good time to share any symptoms or side effects and ask questions.

#### **After finishing treatment:**

You may notice skin reactions. This can take up to six weeks to heal.

- Continue to use mild soap and avoid scrubbing until skin is totally healed.
- After finishing treatment, moisturizing the skin may help the skin; ask your doctor when it is okay to use lotions other than the Miaderm cream. Any lotions used after treatment should still be mild and fragrance free.
- Avoid sun exposure to the treated area after completing treatment. Once your skin is healed, you should use at least SPF 30 sunscreen on the treated area when outside; we would encourage you to still cover the treated area in the sun as much as possible.

# Common side effects of radiation



#### **Fatigue**

Fatigue can affect patients in different ways. To help combat fatigue, plan to rest more frequently throughout the day. A short nap, going to bed early and planning for rest periods between activities can help reduce its impact.

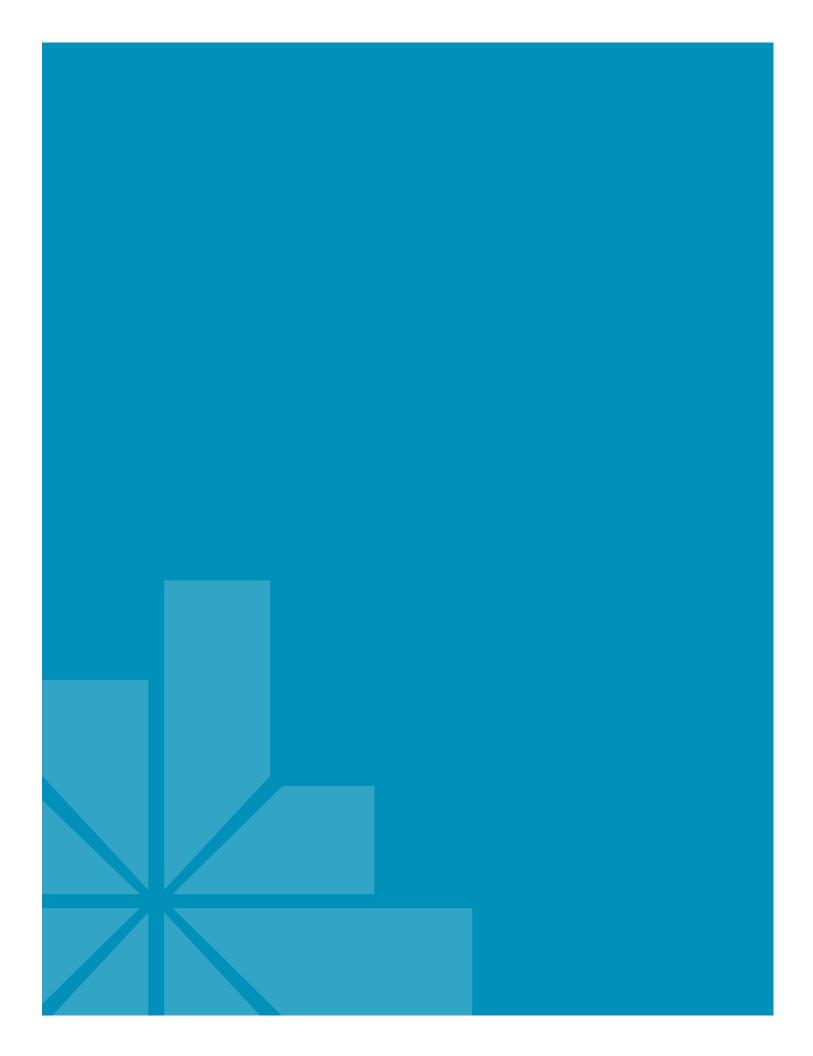
#### Nausea

Nausea is site specific and not common with all types of radiation. If you do have nausea, please notify the nurse or doctor. There are a variety of options available to help you with this. If you are unable to eat well, you may be referred to a dietitian.

#### **Hair Loss**

Hair loss from radiation treatment will be local to the area being treated. For example, if you are being treated for breast cancer, the hair under your arm may fall out. But you will not lose the hair on your head. Hair loss may begin two to three weeks into treatment. The hair will likely grow back in three to six months and may be a different color or texture than it was before treatment.

# UNDERSTAND YOUR LAB TESTS



# **Index of terms**



#### **Blood Urea Nitrogen (BUN)**

BUN is a waste product that comes from protein breakdown in the liver and is excreted by the kidneys. When your kidneys are not working well, the level of BUN in the blood will increase. Dehydration and blood loss can also elevate BUN levels. A low BUN level can be caused by liver disease, a low protein diet or by drinking too much water.

#### Creatinine

Creatinine concentration in your blood depends on: the amount of muscle you have and the ability of your kidneys to excrete creatinine. A high level of creatinine in the blood usually indicates deterioration in kidney function.

#### Your BUN/creatinine ratio

BUN or blood urea nitrogen is a waste product that is removed by the kidneys. This test helps the doctor understand how well your liver and kidneys are working.

#### Sodium (Na+)

Sodium plays an important role in the salt and water balance in your body. The adrenal hormone aldosterone, and the rate of excretion in urine, regulate the blood sodium level. With too much water intake, heart failure or kidney failure can occur because fluid retention can cause a low sodium level in the blood. Low levels can also be caused by loss of sodium in diarrhea, fluid and vomit, or by a deficiency of adrenal hormone. Too much intake of salt or not enough intake of water can also cause a high level.

#### Potassium (K+)

Found inside all cells, potassium's role is maintaining water balance inside the cells and helping to transmit nerve impulses. The level of potassium in your blood is important. Low levels may be found in patients on diuretics or in patients not receiving enough dietary potassium. A low potassium level can cause muscle weakness and heart problems. A high level can be found in kidney disease or in overuse of potassium supplements. Some "salt" substitutes contain potassium instead of sodium, and excessive use of these substances can cause dangerously high levels of potassium in the blood. Adrenal hormone disorders can also alter blood potassium levels.

#### Chloride

Chloride is another element that plays a role in salt and water balance. It is rarely the only element that is low or high. It is an electrolyte that plays an important role in the regulation of blood pressure, blood volume and blood pH levels.

#### Magnesium

This mineral plays an important role in many biochemical reactions, including your heartbeat, nerve and muscle function, bone development, energy production, glucose, blood pressure regulation and protein synthesis.

#### Carbon Dioxide (CO<sub>2</sub>)

Is an odorless, colorless gas. It is a waste product made by your body. Your blood carries carbon dioxide to your lungs. You breathe out carbon dioxide and breathe in oxygen all day, every day, without thinking about it. A  $CO_2$  blood test measures the amount of carbon dioxide in your blood. Too much or too little carbon dioxide in the blood can indicate a health problem.

#### **Albumin**

Approximately two-thirds of the total protein circulating in your blood is albumin. This important protein keeps water inside your blood vessels. When your albumin level is too low, water can leak out into other parts of your body and cause swelling. A low level of albumin in the blood can be caused by malnutrition, too much water in the body, liver disease, kidney disease, severe injuries such as burns or major bone fractures and slow bleeding over a long period.

#### Globulin

This is the group of proteins in your blood that helps fight infections. It's made up of about 60 different proteins. Some play an important role in blood clotting. If your globulin level is abnormal, your doctor may want to measure some of the individual proteins that make up this group.

#### Albumin/Globulin Ratio

A simple way to tell if the albumin or globulin levels in the blood are abnormal is to compare the level of albumin to the level of globulin in your blood.

#### **Total Protein**

This is a measure of the total amount of protein in your blood. A low or high total protein does not indicate a specific disease, but it does indicate that some additional tests may be required to determine if there is a problem.

#### Glucose

Glucose is the chief source of energy for all living organisms. However, abnormally high or low blood glucose levels may be a sign of disease. For example, high glucose levels after 12 hours of fasting may suggest diabetes. Low blood glucose, on the other hand, may be seen with certain tumors or liver disease. A low glucose level may also mean that the blood sample was not handled improperly after it was drawn.

#### Calcium

Calcium is one of the most important elements in the body. 99% of the calcium in the body is in the bones. The remaining one percent is in the body fluids, such as blood, and is very important for the proper function of nerves, enzymes, muscles and blood clotting. High levels can be caused by bone disease, excessive intake of antacids and milk (this is often seen in people with ulcers), excessive intake of vitamin D and overactivity of the thyroid gland. The parathyroid gland is the main regulator of calcium in the body. Tumors of the parathyroid gland may result in very high calcium levels.

#### Alkaline phosphatase (ALP)

ALP is an enzyme that is produced in the organs and in the bones. It is most frequently produced in the liver, and low levels of ALP can indicate poor liver functioning. But it can also be due to a bone-related disorder. Certain drugs may cause high levels too.

#### **Alanine Aminotransferase (ALT)**

ALT is produced mainly in the liver, but also in the kidneys, heart and pancreas. A high level of ALT in the blood is normally caused by damage to the liver.

#### **Aspartate Aminotransferase (AST)**

AST is an enzyme found in the red blood cells, liver, heart, pancreas, kidneys and muscle tissue. When there is damage to one of these areas, more AST is produced and released into the blood.

#### Complete blood count (CBC)

This is one of the most commonly ordered blood tests. A CBC is used to evaluate your overall health and detect a wide range of disorders, including anemia, infection and leukemia.

#### White blood cells (WBC or Leukocyte count)

These cells are produced in the bone marrow and are part of the body's immune system that helps fight off infections.

#### **Absolute Neutrophil Count (ANC)**

Neutrophils are a type of white blood cell. They are the most important WBC in fighting infections. You are at higher risk of infection when this number is low.

#### **Granulocytes (GRAN)**

Immature granulocytes are immature white blood cells. The presence of immature granulocytes in blood test results usually means that your body is fighting an infection or inflammation. When your body is fighting an infection or inflammation, it increases the production of white blood cells (WBCs).

#### Red blood cell count (RBC or erythrocyte count)

RBCs are made in the bone marrow and carry fresh oxygen throughout the body. They are also important in determining blood type. Normal RBC values vary according to gender and age.

#### **Hematocrit (Hct)**

Hct is a measure of the percentage of the total blood volume that is made up of the red blood cells (RBCs). Decreased levels indicate anemia. Increased levels can indicate erythrocytosis. Like other RBC values, the Hct can be altered by many factors, such as hydration status and RBC morphology.

#### Hemoglobin (Hgb)

Hemoglobin is the protein inside red blood cells. The Hgb concentration is a measure of the total amount of Hgb in the peripheral blood, which reflects the number of red blood cells (RBCs) in the blood. Hgb serves as a vehicle for oxygen and carbon dioxide transport.

#### Platelet count

The platelet count is a test that determines the number of platelets in a person's sample of blood. Platelets, also called thrombocytes, are tiny fragments of cells that are essential for normal blood clotting.



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