

# Head and Neck Cancer Education Guide



Cancer Institute

BELTON REGIONAL MEDICAL CENTER
CENTERPOINT MEDICAL CENTER
LAFAYETTE REGIONAL HEALTH CENTER
LEE'S SUMMIT MEDICAL CENTER
MENORAH MEDICAL CENTER
OVERLAND PARK REGIONAL MEDICAL CENTER
RESEARCH MEDICAL CENTER



Dear Patient,

Thank you for choosing us to care for you and your family.

Treatment for cancer of the head and neck region requires a complex, multi-disciplinary approach which means you will be seen by several types of specialized physicians and health professionals throughout your care. While the demanding schedule and detailed information can be overwhelming, we are here to support you.

This booklet is designed to guide and empower you throughout your cancer treatment journey. We ask that you use it as a reference and workbook to educate yourself and your support team.

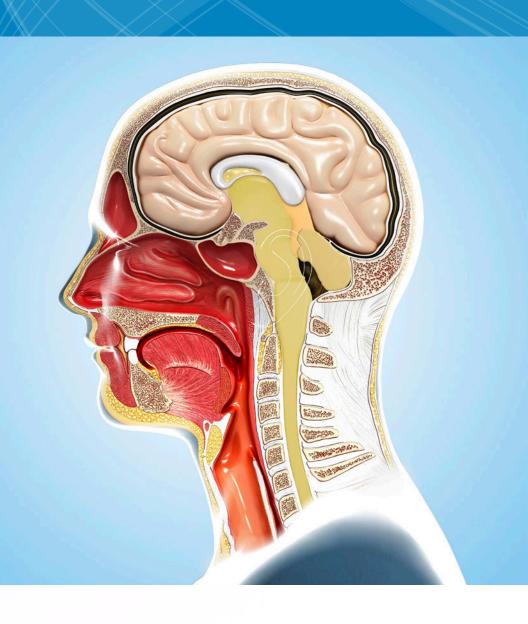
There are blank places for notes and measurements to help keep you organized and informed.

Thank you,

Sarah Cannon Cancer Institute at HCA Midwest Health



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### Diagnosis - What is cancer of the head and neck region?

Unwanted change and rapid reproduction of cells in the head and neck region may create an invasive, cancerous mass. Treatments are designed to remove and prevent reoccurance of these cancerous cells.

### **Before Treatment**

### **BEFORE TREATMENT**

### **Meet your Nurse Navigator**

- Supports patients soon after diagnosis
- Guides through appointments
- Advocates and educates
- Serves as a connection between you and your care team
- Acts as a resource for overcoming barriers

### **Dental appointments**

A dentist will treat any correctable problems and will remove irreparable teeth. Dental work must be completed before initiation of radiation therapy.

### **Speech Language Pathology appointment**

A speech language pathologist (SLP) evaluates your ability to swallow and communicate safely and effectively. Individualized swallowing exercises, voice and communication concerns are treated as appropriate. The treatment program is done proactively and continues throughout cancer treatment to reduce the risk of harmful side effects such as lung infections and malnutrition/dehydration which can cause delays in cancer treatments.

Although it may become difficult to swallow, it is vital to continue swallowing (if cleared by SLP) throughout treatment in order to maintain good muscle function, even if using a feeding tube for nutrition.

Notes:				

### **Before Treatment**

**Establish physical baseline -** Recording your pre-treatment baseline helps set post-treatment goals.

### Hearing

Hearing may be assessed before and/or after treatments by an Otolaryngologist (ENT). Hearing loss may occur as a side effect from treatments and a baseline measure of hearing may be beneficial.

### **Take pictures**

Pictures at baseline and throughout treatment may help identify visual swelling of the head/neck area, allow you to note changes. Date each picture, and keep photos together. It is helpful to wear minimal clothing in pictures to allow for clear comparisons.

### Pictures to take:

- Close-up of face at rest from front and both sides
- Full body picture from front and side

#### Take measurements

Pre-treatment body measurements can assist in identifying physical changes and muscle loss through treatment and into survivorship. These measurements can help you set post-treatment goals and allow you to note measureable progress.

### Measurements to take (use a flexible tape measure)

Measurements (inches)	Pre-treat Date	Date	Date	Date
Height				
Chest (widest point)				
Waist (@ belly button)				
Hips				
Mid-point of R thigh				
Mid-point of R upper arm				
Neck				
Weight (pounds)				

#### **BEFORE & DURING TREATMENT**

### Consume a healthy diet

Eating healthy can help:

- Maintain a healthy weight
- · Prevent delays or breaks in treatment
- Reduce lack of appetite
- Reduce hospitalization time
- Have adequate energy levels (mental and physical)
- Improve body's response to treatments
- · Improve healing ability
- Protect against malnutrition

A cancer diagnosis can change nutritional needs. It is important to meet with a Registered Dietitian (RD) during cancer treatment to maximize your diet.

An RD can provide individual recommendations for preparing and consuming food and drink and provide practical ways to optimize your nutrition.

Sarah Cannon has dietitians on staff who will assist in achieving your nutritional goals. Dietitian services are provided at no cost to Sarah Cannon patients.

Try to stay active with your typical daily activities and hobbies (unless directed otherwise by your physician).

#### **Get active**

- Maintain normal daily activities as able after diagnosis.
   (ex: cooking, cleaning, laundry, shopping)
- The American Cancer Society recommends exercising at least 150 minutes per week (22 minutes each day)
- Strength training increases muscle strength and reduces fatigue greater than cardiovascular exercise.

"In terms of fitness and battling through cancer, exercise helps you stay strong physically *and* mentally."

~ Grete Waitz, Olympic athlete and cancer survivor

Exercise is purposeful movement that has a goal, plan or intention. Keep in mind that as you navigate cancer and physically feel different, your exercise plan may change. We will help you create a personalized exercise plan to meet your goals during and after treatment.

### Four types of exercise to get and stay active

- Aerobic: increases heart rate and can improve endurance, ex: biking, walking
- Strength: challenges muscle groups to improve strength and function, ex: squats, lifting weights
- Balance: challenges feet/ankles and core to improve safety and reduce fall risk, ex: tai chi, standing on 1 leg
- Stretching: improves joint range of motion, ex: yoga and the exercises on the following pages

The above exercises can be combined to maintain and improve function, endurance, strength, and quality of life.

If pain and/or physical limitations are limiting your ability to perform daily tasks as desired, please talk to your physician or wellness team member. We may recommend occupational or physical therapy to help you meet these goals.

### Maintain good posture and range of motion

Good posture is important to support the head and neck, reduce joint pains and muscle fatigue. Cancer treatments may impair posture and mobility, so it is important to practice the following movements every day. These movements should be done with gentle and pain-free range of motion. You may feel a slight stretch, but no pain, numbness, or tingling should occur.

### Practice good posture at all times

**Good Posture** 



**Bad Posture** 



Try these movements in repetitions of 3 each throughout the day.

**Neck rotation** 



**Chin to Chest** 



Look Up



Ear to Shoulder



Try this movement in repetitions of 20 each throughout the day.

**Shoulder Blade Squeeze** 



# Try these movements in repetitions of 3 each throughout the day.

### **Reach Overhead**



**Hands Behind Head** 



Notes:

### **Lateral Reach**



**Hands Behind Back** 



# Try these movements in repetitions of 3 each throughout the day.

### Lateral jaw movement





### Mouth open/close



Notes:						
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			-			

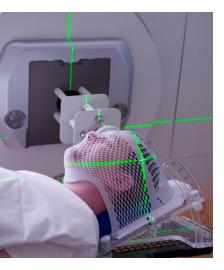
### HOW DO WE TREAT HEAD AND NECK CANCER?

A variety of treatment options are available for head and neck cancer. Your medical team will develop an individualized plan for your specific cancer type and location. In this section, you will find descriptions of each treatment option, why your medical team might choose it, and how it is performed.

### Surgery

A surgeon will perform the physical removal of cancerous tumors, cells and possibly lymph nodes. This will often be followed by a hospitalization for several days and you will receive specific information regarding surgery and post-operative restrictions that are individualized for each patient.

Post-surgical restric	ctions and notes:	



#### Radiation:

- Uses intense beams of light to kill cancer cells (and healthy cells) in a precise area
- May occur pre-surgery to shrink a tumor
- May occur a few weeks after surgery to kill remaining cancerous cells
- Is typically done once daily,
  5 days per week for several weeks
- Lasts approximately 15 minutes per treatment session (Refer to side effects section for more information)

The radiation team is composed of a radiation oncologist, a radiation RN and radiation therapists. There will be a weekly appointment with the radiation oncologist. You will see radiation therapists each visit.

CT "Sim" visit: A planning visit to allow for proper positioning and dosage of radiation. This allows the patient and radiation team to plan for each treatment day. It may take up to 2 weeks between the "Sim" visit and treatments.

Mask: You may be fitted for a thermoplastic mask to be worn during "Sim" visit and treatments. The mask will allow your head to be positioned properly during radiation treatment sessions.

### Chemotherapy

Chemotherapy is the use of anti-cancer medications to:

- Kill cancer cells
- Change cancer cell reproduction

Other notes about treatments.

- Shrink tumors
- Reduce likelihood of cancer spreading

Chemotherapy treatments are overseen by a medical oncologist. A Nurse Practitioner will meet with you to discuss chemotherapy medications and possible side effects for these medications before you receive treatment. Infusion chemotherapy is individualized depending on diagnosis and other factors.

Each treatment day, you will have bloodwork drawn for lab work. The lab work will take approximately 30 minutes. After lab work is completed the pharmacy will prepare chemotherapy medications for you. Registered nurses will administer infusion treatments. These may occur through a surgically implanted port or through IV. Each treatment plan is different so length of each visit may vary.

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### **Ports and PICC Lines**



Ports and PICC lines are inserted into the superior vena cava (a large vein) in the chest/shoulder region. Both devices are used to administer chemotherapy medications and to conduct blood draws.

The area may feel tight or sore, and you may experience general discomfort. Notify your medical team immediately if you begin to feel sharp, stabbing, and/or shooting pains in this area.

#### **Ports**

A port is surgically implanted under the skin, and the area will be sore for up to a few weeks but will reduce over time. The area is susceptible to friction from seat belts and bra straps so it may benefit from increased protection to reduce sensitivity for a short time.

About 2 weeks after port placement, you may perform all desired activities. Ask your surgeon for specific restrictions.

You will still feel a needle prick, but topical medications can be prescribed to numb the area before medications are given and labs are drawn.

#### **PICC Lines**

A PICC line is an external access line through which medications are administered. Use of a PICC line is not as common but may be used for short durations of treatment. A PICC can be inserted in an exam room without general surgery. A PICC line has tubes that hang down on the outside of the skin.



### **PEG** tube

You may have a feeding (PEG) tube surgically placed to help you maintain adequate nutritional intake during treatments. PEG tubes may provide some or all of your nutritional requirements, depending on your specific need.

Keeping the skin, PEG tube, and the oral cavity clean is very important for prevention of infection. Thorough cleaning of the skin and brushing of the teeth/gums/tongue will be required daily.

Patients with PEG tubes must continue to swallow, even if it is only their own saliva (as advised by physician and SLP).

Follow all directions as given by your healthcare team for cleaning and feeding procedures.

Notes about PEG tube surgery and use:	
My PEG Tube Feeding Information	
My calorie goal:	_
My protein goal:	
My fluid goal:	
My daily formula goal is:	
Each can of provides	calories,
grams of protein, and	_ milliliters of water.
My water flush goal is:	
My home nutrition support company is: _	
Contact information:	

### SIDE EFFECTS FROM TREATMENTS AND TIPS TO RELIEVE SIDE EFFECTS

### **Fatigue**

Fatigue is the most commonly reported side effect during cancer treatments. It may occur due to any of the following:

- Surgery
- Chemotherapy
- Radiation
- Healing
- Stress

- Pain
- Ineffective rest
- Not enough exercise
- Inadequate nutrition

Radiation fatigue accumulates over time and worsens as radiation treatments progress. This will continue for weeks after radiation treatments are completed and then decline.

Chemotherapy fatigue may fluctuate in response to medications and treatment schedule.

Fatigue may become so severe that it is necessary to take time off work and alter your responsibilities in your personal life.

Ideas to help cope with fatigue:

- Energy Conservation: Allow others to help with some tasks. Pace yourself throughout the day, take small rest breaks throughout the day rather than large naps.
- Sleep: Get good quality and amount of sleep each night. Stop looking at electronic screens 1 hour before bedtime.
- Don't drink caffeine after 3 pm.
- Consume foods with good nutritional value
- Consume enough calories to allow your body to fight cancer, heal, and perform daily activities
- Stay properly hydrated.
- Exercise increases mental stimulation and generates circulation to improve energy levels. Strive to intentionally exercise 20-25 minutes per day.
- Talk with a licensed mental health therapist or counselor about your change in abilities and roles to alleviate the emotional component of fatigue.

#### Skin side effects

Skin reaction may be noticed after 7-10 radiation treatments of radiation and will continue to advance in severity. Tanning, redness, and or dryness of the skin may occur. Some patients may experience a "radiation rash". In extreme cases a skin breakdown will occur. Please notify radiation team of skin breakdown.

### <u>Ideas to help cope with skin side effects:</u>

- Avoid scratching and irritating skin.
- Gently wash with lukewarm water and soap made for sensitive skin (example Dove or Ivory) and pat dry to clean.
- Avoid sun exposure to the treatment area by covering up with large brim hats and sun protective clothing.
- Avoid swimming pools and hot tubs.
- Avoid shaving or utilize a clean electric razor.
- Avoid utilizing lotions 2 hours prior to treatment time.
- Skin reactions will take time to heal and can last a couple of weeks post radiation completion. Continue the above skin care as long as skin remains red and tender.
- The radiation team will provide a list of physician approved lotions/ointments to utilize, please notify team of any skin conditions or concerns.

### **Mouth Irritations and voice changes**

Radiation will cause a sun tanning effect inside the mouth and will cause salivary production changes, frequently causing dry mouth.

Radiation may alter vocal sound production, changing the ability to speak as desired. Some patients report wet and gurgling voice sounds after swallowing.

It is important to keep mouth clean to minimize infection and for cavity prevention.

### Ideas to help cope with mouth side effects:

- Use a soft bristled toothbrush after every meal.
- Do not use mouth wash containing alcohol.
- Avoid tobacco products and alcohol during cancer treatment time.
- Avoid using denture adhesive during treatments for partials or complete dentures. Denture wear may need to stop if mouth becomes too irritated.
- For relief: Use the following up to 5 times daily: quarter teaspoon of salt, quarter teaspoon baking soda and 8 oz of warm water. Rinse and spit.
- Over the counter products such as Xylimelts have been successful for some in relief of dry mouth.
- Continue swallowing and stay properly hydrated.

### Taste changes

Ability to taste may change throughout treatments. Some foods may become unpleasant or simply have no taste.

These changes make it difficult to get adequate nutrients. A lack of nutrients may result in malnutrition, weight loss and poor ability to heal.

### Ideas to help cope with changes in taste:

- Add a sweetener: maple syrup, agave or nectar
- Add a fat: nut cream, oil, or butter
- Add lemon juice or sea salt

### **Swallowing**

Radiation exposure may result in changes that impact your ability to swallow. These changes may include mouth sores, dry mouth, the feeling of a "lump" stuck in the throat and painful swallowing.

<u>Ideas to help cope with swallowing side effects and to improve</u> ability to swallow food and drink:

- Eat foods that are bland, semi-solid or soft, and easy to swallow.
   Cream soups, cheeses, mashed potatoes, yogurt, eggs, custards, puddings, cooked cereals, ice cream, casseroles, gravies, shakes, and smoothies are good choices.
  - Choose cooked vegetables or canned fruits
  - When eating meats, try ground beef, shredded chicken, or soft and flaky fish
  - Soft and moist protein ideas: deviled eggs, omelets, meatloaf, pot pie, tuna salad, macaroni and cheese, refried beans, cottage cheese, protein shakes
- Make smoothies with soothing fruits such as melons, bananas, and peaches. Add yogurt, frozen yogurt, milk, ice cream, or silken tofu for extra protein.
- Choose soothing room-temperature or cool foods.
- Eat several small meals a day rather than three large ones. Space the meals about 2 to 3 hours apart to get the most comfort.
- Puree or blend foods in a blender to make them easier to eat.
- Increase fluid intake to keep mouth moist. (Blend or moisten foods that are dry and solid.)
- Prepare meals in a crock pot to increase softness.
- Ask your pharmacist for recommendations on swallowing medications. Do not change the medication state without proper consultation from an expert.

Continuing swallowing if cleared by medical staff.
 Continue to swallow saliva, liquid, and food even when
 painful. The muscle group that enables you to swallow must
 be utilized throughout treatment, otherwise muscle wasting
 will occur and cause swallowing to become more difficult
 after treatment. Discuss swallowing treatment with your
 physician.

### Avoid these difficult-to-swallow foods:

- Very cold foods or very hot foods can irritate your throat.
- Alcoholic beverages.
- Tart or acidic beverages and foods, such as citrus fruit juices (grapefruit, orange, lemon, and lime)
- Pickled and vinegary foods (relishes and pickles)
- Tomato-based foods (chili, salsa, pasta sauces, and pizza).
- Salty foods, such as some canned broths and dry soup mixes.
- Coarse or rough-textured foods, such as dry toast, granola, and raw fruits and vegetables.
- Strong or spicy flavorings, such as chili powder, cloves, curry, hot sauces, nutmeg, and peppers.

### **Mental/Emotional concerns**

Head and neck cancer patients have higher rates of depression and suicide compared to patients of other cancer types-both during and after treatments. The increase in depression is due to severity of side effects and dramatic changes in ability to eat, drink, and communicate as the head and neck region is vital for these daily functions. You may experience significant fatigue which impacts your ability to continue life roles as desired for a period of time. Decreases in strength, endurance and ability to taste may continue for years following treatment.

Please discuss your mental and emotional concerns with both your support system and healthcare team. It is important to consider an appointment with a licensed mental health provider.

### Lymphedema

Lymph (a colorless fluid containing white blood cells) travels throughout your body using lymph nodes to fight infection. Lymphedema occurs when the body is unable to move lymph properly and fluid buildup occurs. For patients who have received head and neck cancer treatments lymphedema may occur in the neck, head, chin, face, and mouth.



Lymphedema may occur quickly after cancer treatments or years after completing treatments and

occurs in areas that have been traumatized and/or had lymph nodes removed.

### Signs and symptoms of lymphedema include:

- Swelling and/or tightness of the face, eyes, lips, neck, or below the chin
- · Issues with vision due to swelling in the eyelids
- · Difficulty moving your head, neck, jaw, or shoulders
- Difficulty swallowing
- Difficulty breathing
- Difficulty speaking
- Drooling or difficulty keeping food in the oral cavity while eating
- Nasal congestion
- Long-lasting ear pain
- Scarring (fibrosis of the neck and face)

Swelling may vary daily. If these symptoms arise, your physician may refer you to a lymphedema therapist (a specially trained physical, occupational therapist or speech language pathologist).

Lymphedema therapists utilize specialized, hands-on techniques and tools that help reduce the amount of lymph in the head/neck area. This reduces swelling, stiffness, and pain, allowing for improved swallowing, breathing, and speaking.

### Weight Loss/Malnutrition

Head and neck cancer patients commonly experience decreased ability to eat and drink due to painful and/or difficulty chewing and swallowing that may occur either before diagnosis or as a result of cancer treatments. If swallowing becomes too difficult and nutritional intake is reduced malnutrition becomes a concern.

Losing weight during treatment is not encouraged. If you lose weight during treatment, it means you are not getting enough calories and likely not enough protein, vitamins, and minerals. Patients not only lose fat, but they lose muscle tissue so emphasis on protein intake is given to reduce muscle loss. This will affect your strength and ability to tolerate and complete treatments.

Reducing risk for malnutrition can be achieved by modifying diet to increase what you are able to eat. If you are unable to obtain enough nutrition orally then enteral nutrition (feeding tube) support may be utilized.

# Below are helpful hints to assist you in getting enough good nutrition during cancer treatments.

### Good sources of protein:

- Meats, poultry
- Seafood
- Eggs
- Dairy

- Beans (pinto, black, kidney, etc.)
- Nuts/nut butters
- Lentils and peas
- Protein powders or drinks

### <u>High-calorie additions to foods:</u>

- Avocado
- Coconut Oil
- Nuts/nut butters
- Salad dressing or dips
- Ice cream, whipped cream
- Creamy condiments: mayonnaise, cream cheese, sour cream
- Butter
- Oils (olive, canola, etc.)
- Gravies or creamy sauces
- Cream soups
- Nutrition supplement drinks
- Maple syrup, honey



### Tips to increase your food intake:

- Eat five or six "mini-meals" daily. Plan to eat something every 2-3 hours.
- Keep nutritious snacks nearby keep on your counter, in your car, or in your purse.
- Drink fluids between meals instead of with meals. Fluids with meals can make you feel full.
- Take advantage of when you feel hunger. If you are hungrier in the morning, make breakfast your biggest meal.
- Enjoy breakfast-type foods around the clock. Eggs, pancakes, and waffles are usually easy to eat and can make great meals any time of the day.
- Move around when possible. Walking and other gentle forms of exercise help encourage a better appetite.

Our on-staff dietitians will assist you in determining your dietary needs and will help find different ways to meet your nutrition goals, such as use of certain recipes or modifications to make foods more palatable. Refer to page 16 for specific examples.

### **After Treatments**

#### **AFTER TREATMENTS**

### Follow-up visits

It is **very important** that you attend scheduled follow up visits even after survivorship appointment.

Depending on your specific needs these may be with your medical oncologist, radiation oncologist, and/or ENT. Please do not hesitate to contact us with any further questions, concerns or persisting side effects from treatment.

Continue eating a healthy diet. Continue to be active. A healthy diet and consistent exercise can help with:

- · Improving ongoing side effects after treatment
- · Maintaining a healthy weight
- Prevention of heart disease and diabetes
- · Improving overall physical and mental health
- Reduce risk for re-occurance

Continue to work with skilled rehabilitation therapists as appropriate to improve your physical functioning post cancer treatments. You may also want to:

- Talk with a counselor or psychiatrist
- Journal your thoughts and emotions
- Find a support group
- Journal progress in eating, strength, endurance, weight and body measurements
- Set small, attainable goals for yourself: physical, social and emotional
- Keep a food and exercise log
- Take pictures of face and body for comparison Celebrate each goal you achieve

Sarah Cannon Cancer Institute at HCA Midwest Health's Wellness and Dietitian resources may be utilized beyond treatments and survivorship appointment for guidance in living a healthy lifestyle.

Notes:			

### **After Treatments**

### Survivorship

Following treatments, you will have your "Survivorship Appointment" with a physician or nurse practitioner. The goal of this appointment is to empower you with education and resources to promote a healthy lifestyle following active cancer treatment. It will cover topics such as:

- Review of treatments, side effects, and ways to manage them
- An emphasis on life in the future and finding your "new normal"
- Wellness and nutritional information
- Support resources

### **Online Resources:**

sarancannon.com/nome	Sarah Cannon Cancer Institute
hncliving.org	HNC Living. A Kansas City

based organization for head and neck cancer patients

canceractionkc.org Cancer Action Kansas Citysupport groups, financial

resources

gildasclubkc.org Gilda's Club Kansas City-

support groups

webuild4life.com Kansas City-fitness for those

affected by cancer

cancer.org American Cancer Society-wide

variety of information

headandneck.org Head and Neck Cancer Alliance

# NOTIFY YOUR ONCOLOGIST IMMEDIATELY, REPORT TO THE ER, OR CALL 911 IF YOU HAVE:

- Temperature greater than 100.5
- Uncontrolled vomiting
- Bleeding
- Persistent diarrhea
- Uncontrolled pain or chest pain
- Dizziness
- Any other unusual or worrisome symptoms

# IMPORTANT CONTACT LIST: ENT: \_\_\_\_\_ Nurse navigator: Surgeon: \_\_\_\_\_ Medical oncologist: \_\_\_\_\_ Radiation oncologist:\_\_\_\_\_ Radiation RN: Nurse practitioner(s): Dentist: \_\_\_\_\_ Speech therapist:\_\_\_\_\_ Dietitian: Wellness coordinator:\_\_\_\_ Lymphedema therapist (PT/OT): \_\_\_\_\_ Home health (feeding tube supplies): Home healthcare agency: \_\_\_\_\_\_ Social work:

Therapist/Counselor:\_\_\_\_\_

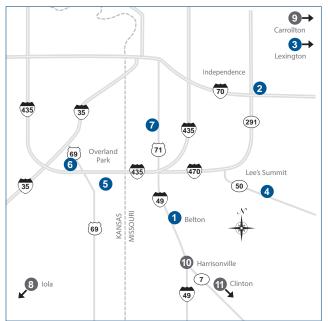
### **Sarah Cannon Cancer Institute Locations:**

- Belton Regional Medical Center in Belton, Mo.; Network-Accredited Cancer Program; (816) 348-1900
- Centerpoint Medical Center in Independence, Mo.; Network-Accredited Cancer Program and Accredited Breast Program for Breast Centers; (816) 698-8290
- Lafayette Regional Health Center in Lexington, Mo.; Network-Accredited Cancer Program (660) 259-6884
- Lee's Summit Medical Center in Lee's Summit, Mo.; Network-Accredited Cancer Program (816) 282-5821

- 5. Menorah Medical Center in Overland Park, Kan.; Network-Accredited Cancer Program and Accredited Breast Program for Breast Centers; (913) 498-7409
- 6. Overland Park Regional Medical
  Center in Overland Park, Kan.;
  Network-Accredited Cancer Program
  and Accredited Breast Program for
  Breast Centers; (913) 541-5550
- 7. Research Medical Center in Kansas City, Mo.; Network-Accredited Cancer Program and Accredited Breast Program for Breast Centers; (816) 276-4700

# COMMUNITY OUTREACH SITES

- 8. Allen County Regional Hospital in Iola, Kan.; (620) 365-1000
- 9. Carroll County Memorial Hospital in Carrollton, Mo. (660)-542-1695 x. 3070
- 10. Cass Regional Medical Center in Harrisonville, Mo.; (816) 380-5888
- 11. Golden Valley Memorial Hospital in Clinton, Mo.; (660) 885-5511



Commission on Cancer® ACCREDITED PROGRAM

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