Welcome and Introduction to your VA HCC Care Team

Dear Veteran,

The following materials were developed to help explain liver cancer and the various care options available to you. Wherever you are in the process, we want to make sure you know you are not alone. We are here to support you and we will work closely with you to make sure you receive the best care possible.

This binder may not have all of the answers to your questions about liver cancer, but we hope that it will serve as a useful resource in addition to your local VA HCC Care Team. It should provide you with a basic understanding of liver cancer. You will also find information about how liver cancer is treated, to help you make more informed decisions, together with your Care Team.

This binder comes in “modules”. Your care team will provide you with different modules that are relevant to you at this time. As your care and needs change, your VA Care/Support team will be able to provide you with additional information and updates, as needed.

My VA Care Team Section

Speaking of your VA support team, the next section, called “My VA Care Team” has your current VA Care Team’s names, numbers and other ways to contact them. You will note that there are additional blank spaces on this form, for you to fill in the names and contact information of other healthcare providers and team members that are important to you. Please ask for assistance with completing this section.

What does that word mean? Definitions Section

You may hear some new or newer words about your health that you are not familiar with, so we have provided a glossary of terms section to help out.

My Diary / Notes Section

We have provided a diary/notes section at the end to assist you with keeping track of your notes, thoughts, and questions while reading about liver cancer, or if something comes up between your healthcare visits. This will help make your visits with your VA Care Team more useful to you, and help you get all of your questions answered.

Consider bringing a small tape recorder or a cell phone to your appointments if you think it would be helpful to record your question and answers with your healthcare team.

We hope you find these materials a useful resource, and we welcome your feedback.

Sincerely,

Your VA HCC Care Team
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Introduction
# My VA Care Team

**My VA:**

**Street Address:**

**Main Phone Number:**

## CONTACT NUMBERS

<table>
<thead>
<tr>
<th>Team Member Name</th>
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<td>Hepatologist</td>
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<td>Interventional Radiologist (IR) / IR Nurse</td>
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<td>VISN Liver Cancer Coordinator</td>
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<td>Other Important Contacts:</td>
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**Introduction**
Who’s Who?

A team of medical doctors who are experts in different areas of liver cancer screening, diagnosis, and treatment will help to develop the best treatment plan for you. The team may include some and/or all of the following:

**Hepatologist (Liver Doctor):** A doctor who takes care of people with disease of the liver. Because this type of cancer is liver-related they work hand-in-hand with the oncologists (cancer doctors) to manage and treat your disease.

**Infectious Disease Doctor:** A doctor who specializes in taking care of patients with infections. These infections can be caused either by bacteria or viruses, including viruses that affect the liver.

**Interventional Radiologist:** A doctor (radiologist) who uses image guidance methods to gain access to vessels and organs. Interventional radiologists can treat certain conditions through the skin that might otherwise require surgery. The technology includes the use of balloons, catheters, microcatheters, stents, and therapeutic embolization.

**Mental Health Providers:** A specialist (psychologist, psychiatrist or social worker) who is there to provide assistance with therapy as needed.

**Nurse:** A professional caregiver working usually in conjunction with a doctor or nurse practitioner that provides healthcare. Nurses work in a wide variety of settings including medical offices, clinics, and home healthcare, to name just a few.

**Nurse manager/coordinator:** To help with appointments and scheduling procedures.

**Nurse Practitioner:** A registered nurse with a graduate degree in advanced practice nursing that can diagnose and treat minor illnesses and perform routine procedures.

**Nutritionist:** The individual on the care team that provides guidance on your diet.

**Oncologic Surgeon:** A surgeon who treats cancer by operating on patients and removing tumors via surgery.

**Oncologist:** A doctor who specializes in the treatment of cancer. There are oncologists who further specialize in medical oncology (treatment of cancer with medicine and drugs), surgical oncology (treatment of cancer with surgery) and radiation oncology (treatment of cancer using radiation).

**Palliative Care Physician:** A doctor who specializes on relieving the pain and other draining symptoms of serious and chronic illness.

**Pharmacist:** The individual on the team trained to dispense medicines and give advice on the best way to take them. Pharmacists are a great resource of information about the medicines you are taking, how they may interact with food, other medicines and the best time of day to take them.

**Primary Care Physician (PCP):** A doctor who is the first point of contact and manages the overall care and health of patients. This doctor refers patients to other specialists as needed.

**Radiation Oncologist:** A doctor who specializes in the treatment of cancer using radiation therapy.

**Radiologist:** A doctor who works with images, x-rays or radiation for medical reasons. A radiologist is expert at reading and interpreting films and scans to understand what is happening to parts of the body (organs, bones, etc.).

**Social Worker:** A social worker is the person on the team supporting efforts to obtain community services and resources, a link to counselling and family treatment and therapy.

**Tumor Board:** A group of doctors who are experts in different areas who review and talk about the medical condition and treatment options of a patient. A tumor board would include a medical oncologist (the doctor that provides cancer drugs), an oncologic surgeon (the doctor that provides cancer treatment with surgery) and a radiation oncologist (the doctor that provides cancer treatment with radiation). Also, a hepatologist, a radiologist, a pathologist, and nurse coordinators are included. This group discussion provides a treatment plan and care plan for a patient and frequently used in cancer cases. Team of health specialists, get together regularly to discuss each case of liver cancer, and make decisions and contribute to your care and management.

**VISN Liver Cancer Coordinator:** The person on the VA Care Team that assists with coordinating your care across the many disciplines (x-ray, imaging, oncology etc.) and, possibly, across facilities.
What is a Liver?

The liver is one of the largest organs in the body and is part of your digestive system. It is shaped like a pyramid, sitting under your right lung inside your ribs.

The liver has many important jobs in keeping you healthy:

- Removes harmful waste from your blood
- Makes bile and enzymes that help you digest food
- Converts food into substances needed for life and growth

DID YOU KNOW?

The average liver weighs between 3 and 4 pounds.
Overview of Cancer

Liver Damage

The liver can be damaged from viruses, too much alcohol use or fat. When this happens the liver cells become inflamed and over time die, which develops scar tissue. When enough of the liver has been replaced by scar tissue, it is called cirrhosis.

People with cirrhosis are at risk for a variety of problems, including liver failure, developing fluid in the legs and stomach and enlarged veins along the esophagus called varices. Per year, 2 to 3 percent of people with cirrhosis also develop liver cancer, so imaging tests are recommended to try and see these lesions as soon as possible.

What is a Liver Tumor?

Cancer begins in cells, the building blocks that make up tissues. Tissues make up the organs of the body. Our body is finely tuned so that normal cells grow and divide to form new cells as they are needed. When normal cells grow old or get damaged, they die, and new cells take their place.

Sometimes, this process goes wrong. Exposure to poisonous chemicals, toxins, radiation, viruses, smoking, too much alcohol, defective genes or changes in genes can disturb this balance. In those situations, older cells do not die and also newer cells start dividing uncontrollably to form excess cells that our body does not need. These extra cells form abnormal clumps of cells or a mass and are called tumors. These excess growths in the liver can be benign (not cancer) or malignant (cancer).

Benign tumors are not as harmful as malignant tumors:

- **Benign tumors:**
  - Are rarely a threat to life
  - Can be removed and usually don’t grow back
  - Don’t invade the tissues around them
  - Don’t spread to other parts of the body

- **Malignant growths:**
  - May be a threat to life
  - Sometimes can be removed but can grow back
  - Can invade and damage nearby tissues and organs (such as the stomach or intestine)
  - Can spread to other parts of the body

Most primary liver cancers begin in liver cells (hepatocytes). This type of cancer is called hepatocellular carcinoma (HCC for short) or malignant hepatoma. This is the most common among all the liver cancers that start in the liver.

Cirrhosis
A state of damage to the liver when the healthy cells have been replaced by fibrosis or scar tissue.

Varices
A set of dilated veins that develop in the linings of the esophagus and upper stomach due to an increase in pressure of the portal veins.

Benign tumor
A tumor that is a growth of noncancerous cells; not malignant.

Hepatocytes
Liver cells

Hepatocellular carcinoma
Cancer of the liver, also known as HCC.

Malignant
Uncontrolled tumor growth that can invade and destroy nearby tissue and that may spread (metastasize) to other parts of the body.
How Do You Get Liver Cancer?

Liver cancer does not occur all of a sudden. It starts in a liver that has been exposed to some of the **risk factors** for the disease. Anything that increases your chance of getting a disease is called a risk factor. Just because you have a risk factor does not mean you will get cancer; not having a risk factor doesn’t mean you won’t get cancer.

The following are risk factors for liver cancer:

- **Age**: Primary liver cancer is more common in people over the age of 60.
- **Alcohol consumption**: People who drink a lot of alcohol are at a greater risk of developing cirrhosis of the liver, which is associated with an increased risk of primary liver cancer.
- **Autoimmune hepatitis**: A chronic disease in which the body’s immune system attacks the normal cells of the liver and causes liver damage. Autoimmune hepatitis can lead to cirrhosis and liver failure.
- **Chronic viral hepatitis**: People infected with hepatitis B and hepatitis C are at very high risk of developing chronic hepatitis, cirrhosis of the liver, and primary liver cancer.
- **Cirrhosis of the liver**: People with cirrhosis of the liver are at an increased risk of developing primary liver cancer.
- **Environmental risks**: Vinyl chloride and thorium dioxide may increase the risk of developing primary liver cancer. People who eat food contaminated with **aflatoxin** (a mold that grows on peanuts and grains) are also at greater risk of developing primary liver cancer.
- **Fatty Liver Disease/steatohepatitis**: Increases risk of liver cancer without the pt necessarily having cirrhosis.
- **Gender**: Primary liver cancer is more common in men than in women.
- **Obesity**: Obese people are at a greater risk of developing primary liver cancer than those who maintain a normal weight.
- **Race/ethnicity**: In the United States, primary liver cancer is more common in Asian Americans and Pacific Islanders than in Latinos, African Americans and Caucasians.
- **Smoking**: Smoking increases the risk of getting liver cancer. Former smokers have a lowered risk than current smokers, but both groups have a higher risk than those who never smoked.

**FOR MORE INFORMATION**

- www.cancer.gov/cancertopics/pdq/treatment/adult-primary-liver/Patient
- www.cancer.med.umich.edu/files/liver-cancer-patient-handbook

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**Risk factors**

Anything that increases your chance of getting a disease.

**Aflatoxin**

A toxin produced by Aspergillus flavus and A. parasiticus, molds which contaminate ground nut seedlings; it has been implicated as a cause of hepatic carcinoma in humans.
# Signs and Symptoms

## What are the Symptoms of Liver Cancer?

Early on in their growth, liver cancers often produce no symptoms. While some people may not have symptoms, others may experience:

- Abdominal pain (usually right upper abdomen that can travel to the right shoulder)
- A swollen abdomen
- **Jaundice** (A yellowish pigmentation of the skin, the whites of the eye and other mucous membranes caused by increased bilirubin in the blood)
- Itchy skin
- Nausea and vomiting
- Weight loss for no known reason
- Weight gain (water gain)

Liver cancer may produce jaundice (a yellow coloring of the skin and eyes), often with a darkening of urine and a pale color to the stool (bowel movement). This is because the growth of the cancer blocks the drainage of **bile** from the liver and the bile’s yellow pigment cannot get into the bowel to color the stool. Other symptoms that may occur are liver pain (especially if the cancer is stretching the fibrous coating that surrounds the liver). The liver does not have nerve endings, so pain is not experienced until the coating is stretched. Liver cancer causes nausea and occasional vomiting. Weight loss for no other reason can be seen.

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**Jaundice**

A yellowish pigmentation of the skin, the whites of the eye and other mucous membranes caused by increased bilirubin in the blood

**Bile**

A substance produced by the liver, and concentrated and stored in the gallbladder. Bile contains many different substances, including bile salts, cholesterol, and bilirubin.

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FOR MORE INFORMATION

- [www.cancer.org/cancer/livercancer](http://www.cancer.org/cancer/livercancer)
- [my.clevelandclinic.org/health/diseases_conditions/hic_liver_cancer_adults](http://my.clevelandclinic.org/health/diseases_conditions/hic_liver_cancer_adults)
- [www.mayoclinic.org/diseases-conditions/liver-cancer/basics/definition/con-20025222](http://www.mayoclinic.org/diseases-conditions/liver-cancer/basics/definition/con-20025222)
How Do You Know That What I Have is a Liver Cancer?

People with symptoms suspicious for liver cancer undergo tests to determine the cause of these symptoms.

Blood Tests and Physical Exam

By now the doctor has likely examined your skin for signs of jaundice (yellowing) and will feel the abdomen for lumps or a change in the size of the liver. The doctor also checks for ascites, which is an abnormal buildup of fluid. Blood is drawn to check for liver function tests, complete blood count, and alpha-fetoprotein (AFP).

Imaging Tests

Imaging for liver cancer is key — unlike other liver diseases, a diagnosis of HCC can be made by solely by imaging (CT scan and/or MRI) alone.

Ultrasound of the Abdomen

An ultrasound is often first imaging that is ordered and is also used for screening for HCC in high-risk patients. A scan can identify a tumor or mass in the liver.

Computed Tomography (CT)

If liver cancer is suspected, then a CT scan may be ordered.

A CT scan combines a series of X-ray views, taken from many different angles. Then, a computer puts these images together to provide different pictures of parts of your body. CT scan images can provide much more information than do plain X-rays to your VA Care Team. For liver cancer, a CT scan can show tumors and even the blood vessels that the tumor might be growing into and/or around. A CT scan can also look at surrounding organs for spread (known as metastasis) of the cancer into the lymph nodes and other areas. You will be given an injection of a special dye called a contrast, so the liver shows up better in the CT scan. The CT scan is reviewed by a radiologist and your doctor within a couple of days. Be sure to confirm and write down your appointment date and time to receive these results.

Magnetic Resonance Imaging (MRI)

An MRI gives similar information to CT scan, but can provide better information in the presence of fatty liver and in looking at subtle differences in tissues of different cell types. The most commonly used contrast dye in MRIs may be safer for a group of patients that have kidney problems or an allergy to iodine.

The MRI may be done to provide additional information for your doctor. It can provide more information around the surrounding blood vessels, organs, and lymph nodes.

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**Ascites**  
An abnormal buildup of fluid in the abdomen.

**Alpha-fetoprotein**  
A protein found at an elevated level in the blood of adults having certain malignancies.

**Ultrasound**  
Sound or other vibrations having an ultrasonic frequency, particularly as used in medical imaging.

**CT scan**  
A technology that uses computer-processed x-rays to produce images (virtual ‘slices’) of specific areas of the scanned object.

**Metastasis**  
The development of secondary malignant growths at a distance from a primary site of cancer.

**MRI**  
A medical imaging technique (x-ray) used to visualize internal structures of the body in detail.
Biopsy

A biopsy removes cells or tissues from your liver so they can be viewed under a microscope by a pathologist to check for signs of cancer. A biopsy can be done in different ways.

Procedures used to collect the sample of cells or tissues include:

- **Percutaneous liver biopsy:** A procedure in which a long needle is introduced through the skin of your chest or abdomen. The needle removes 2 or 3 small samples of liver tissue. This procedure is usually performed on an outpatient basis. If you have a history of bleeding problems your doctor may want to perform a transjugular biopsy.

- **Transjugular liver biopsy:** A transjugular liver biopsy is often advised for people who have a problem with blood clotting or a large amount of fluid in their abdomen. It is done by an interventional radiologist, a doctor who specializes in this type of procedure. During a transjugular biopsy your doctor will insert a small tube into your jugular (neck) vein. X-rays will help guide the tube into a large vein in your liver. A small needle is inserted through the tube and into your liver. The needle removes 2 or 3 small samples of tissue.

- **Laparoscopic liver biopsy:** This is where a special instrument known as a laparoscope, which allows doctors to view the liver (done in the OR by a surgeon), is inserted through a small cut in your abdomen. The laparoscope is a small tube with a camera on the end. The doctor will use instruments attached to the laparoscope to remove tissue samples from your liver. This technique is useful when the doctor wants to take a biopsy from a specific part of the liver. This is the least common type of liver biopsy.

A biopsy is not always needed to diagnose liver cancer. If you are going to have a biopsy, it is important for you to ask your doctor which biopsy method will be used, so you understand what will happen.

**Percutaneous liver biopsy**
Transjugular liver biopsy

What a Pathologist Might See Under a Microscope

Chronic Liver Disease  Cirrhosis  HCC

A pathologist looks at a liver biopsy to assess the severity of your liver disease (done through staging and grading of your liver disease). A normal liver would be uniformly pink and healthy. In chronic liver disease, there can be various stages of scarring. Cirrhosis shows an even greater bridging (like the middle image that looks like white rivers throughout the image). HCC will often look like abnormal cancer cells with an irregular (not necessarily round) appearance such as you see in the image above. If you have had a biopsy, ask your care team to review it with you.

FOR MORE INFORMATION

www.cancer.gov/cancertopics/wyntk/liver/page6
www.cancer.med.umich.edu/files/liver-cancer-patient-handbook
Does my liver cancer mean I need to have a special diet?

People with liver cancer often need to make adjustments to their diet. For most people, a healthy diet follows the DASH diet, which includes lots of fruits and vegetables, whole grain breads and cereals, modest amounts of meats and milk products and a small amount of fat, sugar and salt. When you have liver cancer you need to eat to maintain your strength and deal with the side effects of treatment. As a general rule, you should try to:

- **Take in enough calories** to prevent weight loss and improve nutrition
- **Limit the amount of salt (sodium)** in your diet to 2,000 mg (one teaspoon) each day if you have swelling in your legs or feet or if you have a buildup of fluid in your abdomen
- **Think small.** Eat six to eight small meals a day instead of two to three larger meals. Consume them in two to three hour intervals to prevent long periods of going without food
- **If you have trouble chewing,** consider juicing as a supplement. For the healthiest juices, include more vegetables than fruits. For example, juice one carrot, a cucumber, a small beet, a piece of ginger, and a small apple. Have your juice with a serving of protein, for example Greek yogurt in the morning or scrambled or hard-boiled eggs
- **Choose lean cuts of poultry, fish, beans, nuts and seeds** to help your liver digest them more easily
- **Avoid alcohol.** If you need help with this, please let your VA Care Team know, so that they can provide you with counseling and other alcohol and drug support

**Diet restrictions if you have ascites**

Ascites is characterized by fluid accumulation in the space between the internal organs and the wall of the abdomen (called the **peritoneal cavity**). Symptoms include a distended abdomen, difficulty breathing and a feeling of pressure or fullness in the belly. This condition is a frequent complication and can become life threatening when the fluid becomes infected. The management of your diet, especially changes in sodium in your protein intake can help alleviate those symptoms.

Ascites causes a decrease in the rate at which your kidneys filter sodium, resulting in sodium retention. If you have ascites you need to restrict your sodium intake to less than 2 grams per day. Your doctor may prescribe medicine, a diuretic (water pill) to help increase blood sodium levels and remove excess water.

**Peritoneal cavity**
The space between the internal organs and the wall of the abdomen.
As much as 4 gallons of fluid can leak into the peritoneal cavity. Protein also leaks into the peritoneal cavity along with the fluid. Your doctor may want to remove some of this fluid with a procedure, called a **paracentesis**. With a paracentesis a great deal of protein is lost as the fluid is removed. Your Care Team will advise you on how best to supplement your diet with dietary protein if you have to undergo this procedure.

**How do I reduce salt in my diet?**

Sodium is a mineral found in the body and the food we eat. Salt is the main source of sodium in our diet. For a low sodium diet you should consume no more than one teaspoon (2,000 mg) of **sodium each day**. Although salt is the most common source of sodium, sodium can be found in other types of food. Softened or bottled water and even some medications contain sodium. You need to check the labels of everything you eat and drink.

In general, avoid any food that has more than 400 mg of sodium per serving. The best choices are those foods that contain 200 mg or less of sodium.

**DID YOU KNOW?**

The average person’s diet contains 4,000 to 6,000 mg of sodium each day.

**ChooseMyPlate.gov**

**Paracentesis**

Removal of the fluid from the peritoneal cavity.
Tips for reducing salt:

• Cook low sodium meals at home and freeze them
• Cook with fresh or unprocessed foods whenever possible; avoid canned foods
• If necessary, look for convenience or processed foods containing less than 200 mg of sodium
• If necessary to eat frozen meal, look for lower sodium content items
• Look for sodium free brands of canned foods, or rinse the food with water to reduce some of the sodium
• Experiment with new spices and herbs to flavor food without adding salt

Tips when dining out:

• Avoid fast food restaurants /chinese food (soy sauce)
• Order broiled meat or fish
• Order sauces on the side and use very small amounts
• Use a small amount of condiments such as mustard, ketchup and salad dressing
• Avoid bacon, cheese and croutons in salads

Nutrition specialists are available for you to talk to during your clinic visits to offer suggestions and guidance. They will help prepare a diet plan for your treatment.

Cancer treatment can cause side effects that lead to eating problems

Cancer treatments are designed to kill cancer cells but these same therapies also can damage healthy cells and cause side effects. Some of the more common eating problems experienced with cancer treatment include:

• Appetite loss
• Changes in taste or smell
• Constipation and/or diarrhea
• Dry mouth
• Lactose intolerance
• Nausea
• Vomiting
• Sore mouth
• Sore throat and trouble swallowing
• Weight gain
• Weight loss
You won’t know what, if any, eating problems or side effects you may experience with your cancer treatment until it starts. If you do have any problems, they may be mild and many can be controlled. Here are some things to do and helpful tips before your treatment starts:

• Eat a healthy diet before treatment starts. This will help you stay strong during treatment and lower your risk of infection
• Go to the dentist. It is important to have a healthy mouth before you start your cancer treatment
• Fill the refrigerator, cupboard, and freezer with healthy foods. Make sure you include foods you can eat even when you feel sick
• Cook some foods ahead of time and freeze in meal-sized portions
• Foods like ginger and peppermint can help with some of the common side effects of cancer treatment. Encapsulated ginger can help reduce nausea. You can try a 200 mg supplement three times a day or add 1/8 tsp of fresh grated ginger to hot tea. Peppermint hard candies help with dry mouth and manage nausea.
• Talk with your nurse, doctor, or dietitian about what to expect or any concerns you may have. They can help with many types of eating problems

FOR MORE INFORMATION

www.cancer.gov/cancertopics/wyntk/liver/page11
www.cancer.med.umich.edu/files/liver-cancer-patient-handbook
www.dashdiet.org
Palliative care is an active approach to care that allows a team of healthcare professionals to get to know patients, their families and caregivers to ensure the treatment provided match their goals rather than those of the health team or health plan.

Energy is spent making sure symptoms are well understood, recognized and treated appropriately to avoid and relieve pain and prolong life. Palliative care involves many different areas, including nutrition, expert symptom management, help navigating the healthcare system, psychosocial and spiritual support.

Doctors, nurses, social workers, psychologists, pharmacists and nutritionists make up this team. There are palliative care specialists at all VA hospitals, and your VA Care Team will make sure that you will be evaluated soon after you are diagnosed with liver cancer. The palliative care team works in partnership with your doctor to provide an extra layer of support for you and your loved ones.

Palliative care changes along with the course of your disease. In the initial stages of becoming diagnosed and learning about your illness, palliative care may involve more of an approach centered on helping you and your loved ones learn about the what kinds of signs and symptoms that you could possibly experience or what types of foods are best suited for someone taking the types of medicines you may be prescribed. Later it may be more focused on helping you understand how you can avoid a certain side effect or help manage your pain.
What is the role of palliative medicine in liver cancer?

In advanced stage or incurable liver cancer where the tumor (or tumors) progressively grows and causes various uncomfortable symptoms, palliative care can offer relief to some of these symptoms. In these situations, palliative medicine specialists work with the VA Care Team to formulate a plan to provide expert guidance for the treatment of pain, loss of appetite, nausea, vomiting, fatigue and breathing difficulties associated with advanced stage of the disease. They also offer help and support to you and your family regarding various treatment choices already been offered as part of the liver cancer treatment.

Palliative care and pain

Pain needs to be controlled or it will interfere too much with what you want to accomplish on a daily basis. There are pain specialists at the VA who will help to relieve your pain. Tell one of your health care team members about your pain so that you can decide on the best medication to alleviate the pain.

For more severe pain, you may require morphine-based or opiate medications. You may require higher doses of these medications as your disease progresses, but this is a sign that you are developing tolerance to the effects of the medication. It is not a sign of addiction. The goal is for you to be pain-free, or have it be controlled well enough, without suffering intolerable side effects like sleepiness. You should be aware that you cannot drive or operate any machinery when you are taking opiate medications. You should be able to speak freely about your fears and concerns with your doctor.

Is my liver cancer a risk for my family?

Liver cancer itself is not contagious. Your family should be reassured that they cannot get cancer from being around you. It cannot be transmitted to them.

Viral hepatitis, which can lead to liver cancer, can be transmitted only if there is blood-to-blood contact. Consider keeping some gloves available should someone need to help you with cleaning up after cuts or injuries. There is a vaccine for some forms of hepatitis but not for Hepatitis C.
Coping with your disease

What can I do to cope with the diagnosis of liver cancer?

Receiving the diagnosis of liver cancer is difficult. We understand that life is different after a cancer diagnosis. Some people may accept it positively but others see difficult times ahead. Accepting the diagnosis might take a while. You may react with fear because of the unknown and the uncertainty involved. Denial and anger are also common feelings experienced by people with liver cancer and their family. Guilt over lifestyle issues that led to the diagnosis may also be a factor. There are no easy answers, but the following may be helpful:

- **Learn as much as you can about liver cancer**: The more you know, the better able you are to ask important questions about your options for treatment, side effects, and prognosis and to take the necessary action.
- **Seek support**: If you have friends or family members, they can be very helpful in getting through the first stages when you find out your diagnosis. They can also help with practical details like managing your home and pets when you go into the hospital for treatment. They can also give you the emotional support that you need.
- **Exercise**: It is important to keep exercise a part of your routine. It can be as simple as taking a walk with a friend or loved one but remember to take time to move your body as much as you are able.
- **Get adequate sleep**: All of the activity that accompanies your new diagnosis can be draining. Be sure to get enough sleep to allow yourself to feel adequately rested.
- **Take control of your nutrition**: Your diet is very important as you enter treatment for your disease. Learn what types of foods you should and should not be eating. Inform yourself so you can make the best decisions for you.
- **Be aware of your pain**: If you are in pain be sure to talk to a member of your VA Care Team. They can find ways to help you manage your discomfort and have tips for living as pain-free as possible.
- **Reach out to a member of your VA Care Team**: To help you find a counselor, a support group or other support networks to assist you during this time. It helps to talk to others with the same illness.
- **Take control of your situation**: Make sure you are doing everything you can to control the pieces of the journey that you can. Ask your VA Care Team about living wills and Advanced Directives.
- **Other supports**: Many people find that their spiritual beliefs or a belief in something greater than themselves is a comfort at this time.
What are Advance Directives?

People have the right to make decisions about their own treatment. **Advance Directives** are a way to make your wishes known about what to do in case your heart stops beating or you stop breathing. A DNR or “Do Not Resuscitate” order may be placed to prevent interventions from being carried out, but you do have the right to refuse a DNR and have everything done to keep you alive.

There are other medical treatments that you should discuss with your doctor, such as drawing blood, feeding, and others. You should make your wishes known about these treatments in advance. It’s important to keep in mind that if you should choose not to receive or to stop treatment to control the disease, medical care to promote your well-being (palliative care) continues. This type of care includes treatment to manage pain and other physical symptoms, as well as support for the psychosocial and spiritual needs of you and your family.

What are the next steps after advance directives have been completed? Where should advance directives be stored?

A member of your VA Care Team or another professional should review the documents to make sure they’re filled out correctly. Most states require that signing of the documents be witnessed. You should make copies of the documents and put the originals in a safe but easily accessible place. Give copies to your doctor, hospital, and family members. You may also want to keep in their wallet a card with a written statement declaring that you have a living will and medical power of attorney and describing where the documents can be found. A copy of your advance directives will be scanned into your VA electronic chart.

**Advance Directives**

Legal documents that allow people to communicate their decisions about medical care to family, friends, and health care professionals in the event that they are unable to make those decisions themselves—for example, due to being unconscious or in a coma.
Can I change my Advance Directives?
Yes. The process of discussing and writing advance directives should be ongoing, rather than taking place just once. This way you can review the documents from time to time and modify them if your situation or wishes change. Even after advance directives have been signed, you can change your mind at any time. To update your documents, talk to your VA Care Team and loved ones about the new decisions you would like to make. When new advance directives have been signed, the old ones should be destroyed.

Do the legal requirements for advance directives vary from state to state?
Yes. Each state has its own laws regarding advance directives. Therefore, special care should be taken to follow the laws of the state where you live or is being treated. It’s possible that a living will or medical power of attorney signed in one state may not be recognized in another.

What is a Health Care Proxy and why do I need one?
There may be a time when decisions need to be made about your health and you may not be able to make them. It is important to discuss your wishes with someone whom you trust to carry them out. A Health Care Proxy is a legal document that names a person to act on your behalf and make those decisions if a time comes when you are not able to do so. Once the document is completed you continue to make your own health care decisions as long as you are able to do it. If a time comes when you are not able to communicate your wishes, the health care proxy allows your wishes to be known, via your chosen person, who acts on your behalf. Make sure to discuss who you picked as your healthcare proxy with your family, your VA Care Team, and your social worker.

What is a financial proxy?
In addition you may want to put a financial proxy or power of attorney in place, which gives someone you trust the authority to handle financial transactions on your behalf. This person (or “agent”) can handle things as simple as sorting your mail and depositing Social Security checks to more complex as reviewing your retirement accounts and other investments. Your agent can be a loved one or family friend or a financial professional.

Your financial power of attorney ends if:
• You revoke it. As long as you are mentally competent, you can revoke a financial power of attorney at any time
• At the time of your death. That means you cannot give your agent authority to handle things after your death, such as paying your debts, making funeral arrangements or transferring property to the people who inherit it. If you want your agent to have the authority to wind up your affairs after your death, use a will to name that person as your executor.
• No agent is available. To avoid this you can name an alternate agent in the document.

Of note: Health Care Proxy ends at death.

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<tr>
<th>Health Care Proxy</th>
<th>Financial proxy</th>
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<td>A document that allows a patient to appoint someone to make health care decisions in the event that they are not able to do so. Once the document is drafted, the primary individual continues to be allowed to make health care decisions as long as they are still able to do so.</td>
<td>Also known as a durable power of attorney, a legal document that authorizes someone (an “agent”) to make financial transactions on your behalf. These transactions can range from depositing checks to managing your investments.</td>
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Cancer Survivorship

After being diagnosed with cancer you may find your priorities have changed. Some people with cancer say they appreciate life and their loved ones more. At the same time, it is normal to be concerned about your health and unsure of how to cope with life after treatment. What happens when regular visits to your doctors stop?

Cancer survivorship can be defined as:

- Having no disease after the completion of treatment
- The process of living with - or living without - cancer. With this definition, survivorship begins with diagnosis. It includes people who continue to have treatment to either reduce risk or recurrence or to manage chronic disease

You may hear the term “cancer survivor” used to describe a specific period of time a survivor is experiencing. For example, an acute survivorship describes the time when a person is being diagnosed and/or is in treatment for their disease. An extended survivorship describes the time immediately after treatment is completed, usually measured in months, while a permanent survivorship describes a longer period, usually measured in years.

Surviving cancer: What should I expect?

At the end of your treatment it is normal to have mixed emotions. You may be relieved that the treatment is over yet some anxiety about what the future holds. The goals of survivorship care are to perform surveillance for cancer recurrence and to manage complications of the cancer and its treatment through regular clinic visits and ongoing education and support. At the first visit to the Survivorship Clinic you will receive an individualized treatment summary and surveillance plan. During following clinic visits, you and your care team will review the treatment summary together and discuss how best to maximize your health, quality of life and longevity through:

- Individualized surveillance and screening guidelines
- Wellness education tailored to your liver cancer and treatment history
- Psychosocial support for you and your family
- Healthy living recommendation

By the end of this visit you will leave with a written plan tailored specifically to your needs. A copy is also sent to your primary care physician. Referrals to other services such as physical therapy, nutrition, mental health providers etc. can be made from the clinic. The template for the Joint Survivorship Agreement is found on the next pages.

FOR MORE INFORMATION

www.cancer.gov/cancertopics/factsheet/support
www.cancer.net/survivorship/about-cancer-survivorship
www.hopkinsmedicine.org/liver_tumor_center/treatments/palliative_care.html
www.rocketswag.com/medicine/senior-care/hospice-care/Hospice-Care-For-Liver-Cancer.html
The Treatment Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

<table>
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<th>Follow-up care</th>
<th>When/How Often?</th>
<th>Coordinating Provider</th>
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<td>Medical oncology visits</td>
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<td>Lab tests</td>
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<td>Imaging</td>
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Potential late effects of treatment(s):

Call your doctor if you have any of these signs and symptoms:

- Needs or concerns:
  - Prevention and wellness: __________________
  - Genetic risk: __________________
  - Emotional or mental health: __________________
  - Personal relationships: __________________
  - Fertility: __________________
  - Financial advice or assistance: __________________
  - Other: __________________

- Referrals provided:
  - Dietician
  - Smoking cessation counselor
  - Physical therapist or exercise specialist
  - Genetic counselor
  - Psychiatrist
  - Psychologist
  - Social worker
  - Fertility specialist or endocrinologist
  - Other:
Before liver cancers can be treated, they need to be staged. **Staging** is a way of describing the severity of a person’s cancer based on the size or reach of the primary tumor and whether or not cancer has spread in the body. Staging also helps the care team determine the best way to treat your disease.

There are a number of staging systems that can be used. Some staging systems cover many types of cancer; others focus on a certain type. Most staging systems include the following common characteristics:

- Where the tumor located and what is the cell type
- How big is the tumor
- Has the cancer spread to any lymph nodes
- Number and size of tumors (primary tumors and presence of any metastatic tumors)
- Tumor grade (how closely do the cancer cells look like normal cells and tissue)

**Staging Systems**

Several systems for liver cancer staging are currently used. The **Barcelona Clinic Liver Cancer (BCLC)** is used in HCC and is an algorithm that combines both tumor characteristics and liver function to stage your liver disease. The **Milan Criteria** is a staging system used for liver transplant.

A third system, the TNM system is based on imaging tests (ultrasound, CT, or MRI scan) and other tests. **The TNM system** for staging contains 3 key pieces of information:

- **T**: Describes the number and size of the primary tumor(s), measured in centimeters (larger or smaller than 5 cm), and whether the cancer has grown into nearby blood vessels or organs
- **N**: Describes the extent of spread to nearby lymph nodes
- **M**: Indicates whether the cancer has spread (metastasized) to other parts of the body (for example, the lungs and bones)

Other scoring systems that contribute to these staging systems include the **MELD** scoring system and the **Child-Pugh** score. The MELD score calculation is based on 3 objective variables laboratory tests that is useful in determining prognosis and prioritizing allocation of liver transplants.

The Child-Pugh score is a cirrhosis staging system and a measure of liver function. Many people with liver cancer also have cirrhosis and in order to treat the cancer, doctors need to know how well the liver is working. This system is based on the results of 5 factors, 3 lab tests and two clinical symptoms. Based on these factors, liver function is divided into 3 classes. If everything is normal, then liver function is called Class A. If mild abnormali-
ties are present it is termed Class B and severe abnormalities are Class C.

Both the MELD score and Child-Pugh score provides your healthcare team important information about the stage of your disease and the best treatment plan for you.

Your ability to take care of yourself also is taken into consideration in the staging process. This is considered in the “Performance Status” or PST. The scale ranges from Stage 0 (fully active) to Stage 4 (totally bedridden).

The VA utilizes the BCLC system to stage your disease and determine a treatment plan. The algorithm is shown below:

**The BCLC Staging System**

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**Very Early Stage**
- Single < 2cm
  - PST 0, Child-Pugh A
  - HCC
    - Single
    - HVPG < 10 or T. bili < 1.5
  - Liver Transplantation

**Intermediate Stage**
- Multinodular, PS0
  - PST >2, Child-Pugh C
  - Advanced Stage
    - Portal Invasion, N1, M1, PS1-2
    - Symptomatic Treatment
  - Transarterial Chemoembolization
  - Sorafenib
  - New Agents/ Clinical Trials

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For More Information:

- www.cancer.gov/cancertopics/wyntk/liver/page6
- www.cancer.org
What Treatment Options Are Available for Liver Cancer?

The decision as to what treatment is best for your liver cancer depends on many factors:

- Size, number and location of the tumors
- Overall liver function
- Your age and general health

Different types of treatments are available for patients with liver cancer. Some treatments are standard (the currently used treatment), and some are being tested in a clinical trial. A clinical trial is a research study meant to help improve current treatments or obtain information on new treatments for patients with cancer. When clinical trials show that a new treatment is better than the standard treatment, the new treatment may become the standard treatment. We encourage you to think about taking part in a clinical trial. If there is an appropriate clinical trial for you your doctor or nurse will talk to you about it.

Six types of standard treatment are used:

Surgery

Surgery is the most common treatment for cancer of the liver. There are many types of surgery depending on the stage of the liver cancer.

Resection (partial)

If the liver tumor is small and has not spread, surgery to remove the part of the liver where cancer is found (a partial resection) may be done. This operation is only done if you are healthy enough for surgery and all of the tumor can be removed while leaving enough of the healthy liver behind. A small portion of tissue, an entire lobe, or a larger portion of the liver, along with some of the healthy tissue around it is removed. The remaining liver tissue takes over the functions of the liver and may regrow.

Prior to this operation you will first have imaging studies, such as a CT or MRI to see if the cancer can be completely removed. Even with these kinds of tests, during surgery the cancer could be found to be too large or wide spread to be removed and the surgery is cancelled.

A resection is a major operation. Because a great deal of blood passes through the liver, bleeding after surgery is a primary concern. The liver usually makes substances that help the blood clot. Damage to the liver before the surgery and during the surgery itself can add to the potential bleeding problem. Other possible side effects are similar to those seen with other major operations and include complications from anesthesia, blood clots, infections and pneumonia.
Treatments and Medication

Because the remaining liver still has the underlying disease that led to the cancer, sometimes a new liver cancer can develop after the surgery.

The recovery time for the laparoscopic and open surgeries may vary from person to person. In general, someone undergoing an open liver resection can expect to be in the hospital for 5-10 days and may not return to full activity for 6-8 weeks after surgery. Someone undergoing a laparoscopic liver resection can expect to be in the hospital for 3-5 days and can usually return to full activity between 3-6 weeks after surgery.

Liver Transplant

In a liver transplant, the entire liver is removed and replaced with a healthy donated liver. Usually only people with early, small (1 tumor smaller than 5 cm across or 2 to 3 tumors no larger than 3 cm) liver cancer are candidates for a liver transplant. A liver transplant may be done when the disease is only in the liver, and a donated liver can be found. With a transplant, not only is the risk of a second new liver cancer reduced but the new liver will function normally.

A limitation of liver transplant is the number of livers available for patients needing this surgery. Only about 6,000 livers are available for transplant each year, most used for patients with diseases other than liver cancer. These livers come from people who have just died, however in recent years a small number of patients have received part of a liver from a living donor for transplant. A liver donor is usually a spouse, close friend or relative who is willing to give a portion of their liver for transplant. The liver can regenerate over time if part of it is removed. There are risks of the surgery for the donor, so this cannot be taken lightly. Less than 250 living donor transplants are done in the United States each year, and only a small number of them are for patients with liver cancer.

People needing a liver transplant must wait until a liver is available, which can take too long for those with liver cancer. In this case, other treatments (ablation therapy or chemoembolization) may be given as needed. Like a partial hepatectomy, a liver transplant is a major surgery with serious risks (bleeding, complications from anesthesia, blood clots, infection, pneumonia, etc.). There are additional risks after a liver transplant.

People who get a liver transplant have to be given drugs to suppress their immune system to prevent their body from rejecting the new liver. These drugs have their own risks and side effects, especially the risk of getting serious infections.

Liver transplant
An operation that replaces the liver with a portion of a liver (from a living donor) or an entire liver (from a deceased donor).
By suppressing the immune system, these drugs might also allow any remaining liver cancer to grow even faster than before. Some of the drugs used after a liver transplant can cause high blood pressure, high cholesterol, diabetes, can weaken the bones and kidneys and can even lead to a new cancer. After a liver transplant, regular blood tests are important to check for signs of the body rejecting the new liver. Sometimes liver biopsies are also taken to see if rejection is occurring.

If you have a liver transplant you can expect to remain in the hospital for 5 to 7 days. After you leave the hospital you can expect to be carefully monitored for the first month. The monitoring will reduce in frequency over time.

**Ablation Therapy**

This minimally invasive approach uses microwave or radiofrequency energy to in effect burn your tumor. Your radiologist or surgeon will insert a needle into your tumor through a small incision in your skin. Heat will be transmitted through the tip of the needle to your tumor, thereby killing the tumor. **Ablation therapy** can be done as an outpatient, or in some cases, you will stay overnight in the hospital. Different types of ablation therapy are used for liver cancer:

**Radiofrequency ablation (RFA)**

Radiofrequency ablation (RFA): The use of special needles that are inserted directly through the skin or through an incision in the abdomen to reach the tumor. High-energy radio waves heat the needles which kills cancer cells. This procedure is usually done during a short stay in the hospital. Most patients are admitted the day prior to the procedure. An intravenous catheter (IV) is placed, and medications, including antibiotics, are administered. On the morning of the ablation, the patient is brought to the Interventional Radiology or CT suite, where an anesthesiologist may put you to sleep. The procedure usually lasts 1-2 hours. Following the ablation, the patient is brought to the recovery unit, where they are observed for several hours. Once cleared, they go back to their room, where they are watched for any signs of complication(s).

Though the incision that is made in the skin is small, it is common to have some abdominal discomfort and nausea after the procedure. These symptoms are most severe during the hours immediately after ablation and are usually significantly better by the next day. Pain and nausea medications may be provided to decrease the severity of symptoms. Most patients go home the day after the procedure with pain and nausea medications, if needed. Depending on the size and location of the treated area, an antibiotic may be prescribed to decrease the risk of infection.

**Ablation therapy**

Ablation therapy is a type of minimally invasive procedure used to treat/kill abnormal liver tissue using heat (radiofrequency ablation, RFA), extreme cold (cryoablation), lasers or chemicals.
The risks of ablation include bleeding; infection; worsening liver or kidney function; damage to the organs surrounding the liver; and adverse reaction to anesthesia or to the contrast that might be used to visualize the tumor(s). You may need RFA more than once. This is a common treatment for small tumors. You cannot have RFA if the cancer is larger than 3 to 4 cm or close to any major blood vessels.

Other Types of Ablation Therapy

- **Microwave therapy**: A type of treatment in which the tumor is exposed to high temperatures created by microwaves. This can damage and kill cancer cells or make them more sensitive to the effects of radiation and certain anticancer drugs.

- **Percutaneous ethanol injection (PEI)**: A cancer treatment in which a small needle filled with pure alcohol (ethanol) is injected directly into a tumor to kill cancer cells. Several treatments may be needed. Usually local anesthesia is used, but if there are many tumors in the liver, general anesthesia may be used.

- **Cryoablation**: A treatment that uses an instrument to freeze and destroy cancer cells. This type of treatment is also called cryotherapy and cryosurgery. The doctor may use ultrasound to guide the probe into the tumor and then very cold gasses are passed through the probe to freeze the tumor, killing the cancer cells. This method is used to treat larger tumors than other ablation techniques, but it sometimes requires general anesthesia (where you are put to sleep).

- **Electroporation therapy (also called irreversible (electroporation or IRE))**: A treatment that sends electrical pulses through an electrode placed in a tumor to kill cancer cells.

Possible side effects after ablation therapy include abdominal pain, infection in the liver, and bleeding into the chest cavity of abdomen. Serious complications are uncommon with ablation therapy, but they are possible.

**Embolization Therapy**

_Embolization therapy_ is used for patients who cannot have surgery to remove the tumor and typically whose tumor has not spread outside the liver. Embolization is a procedure that injects substances to try and block or reduce the blood flow to cancer cells in the liver. It can be used for tumors that are too large to be treated with ablation (usually larger than 5 cm). It can also be used together with ablation to enhance the tumor-killing ability of ablations.

The liver has two blood supply systems, the portal vein and the hepatic artery. Blocking the branch of the hepatic artery feeding the tumor helps kill off the cancer cells, but leaves most of the healthy liver cells unharmed because they get their blood supply from the portal vein.

Your interventional radiologist will insert a narrow tube (catheter) into the artery in your arm or leg. He or she will inject microscopic beads into the artery that feeds the tumor - this will block flow of blood into that area of the liver. Sometimes anticancer drugs will be injected in addition to the microscopic beads. This blockage deprives the tumor of oxygen and other substances so it will no longer grow.
Embolization does reduce some of the blood supply to the normal liver tissue, so it may not be a good option if your liver if your liver is not functioning well enough.

There are 3 main types of embolization:

**Arterial Embolization**

There are 3 types of arterial embolization, bland (or small little beads), chemo (where the artery is plugged with small beads infused with chemotherapy agents) and radio (where the beads placed in the artery give off small amounts of radiation).

**Bland arterial embolization (TAE, small beads)**

Bland arterial embolization is also known as trans-arterial embolization (or TAE). In this procedure a thin, flexible tube (known as a catheter) is put into an artery through a small cut in the wrist or groin and threaded up to the hepatic artery in the liver. A dye is usually injected into the bloodstream at this time to help the doctor monitor the path of the catheter via angiography, a special kind of x-ray. Once the catheter is in place, small little beads are injected into the artery to plug it up.

**Chemoembolization (TACE, chemo)**

This approach is also known as trans-arterial chemoembolization (or TACE) and combines embolization with chemotherapy. This is most often done by using tiny beads that send out a chemotherapy drug for the embolization. TACE can also be done by giving chemotherapy through the catheter directly into the artery, then plugging up the artery.

**Radioembolization (RE, radio)**

Radioembolization combines embolization with radiation therapy. This is done by injecting small radioactive beads into the hepatic artery. Brand names for these beads include TheraSphere® and SIR-Spheres®. Once infused, the beads lodge in the blood vessels near the tumor, where they give off small amounts of radiation to the tumor site for several days. The radiation travels a very short distance, so its effects are limited mainly to the tumor.

**What to expect:**

Most patients are admitted the day prior to the procedure. An intravenous catheter (IV) is placed, and medications, including antibiotics, are administered. On the morning of the embolization, you will be brought to the Interventional Radiology suite, where the insertion site will be cleaned to decrease the chance of infection, and you will be given sedative medications. The sedative medications affect patients differently. Some people remain asleep throughout the procedure. Others are awake but are very relaxed. Every effort is made to assure that patients are comfortable.
The procedure usually lasts 1-2 hours. Following the embolization, you will be brought to the recovery unit, where you will be observed for several hours. Once cleared, you will go back to your room, where you will be watched for any signs of complication(s).

In order to minimize any risk of bleeding, it is important for patients to lie flat and to keep their legs straight for 6 hours after the embolization procedure. This is challenging for some patients but is important in order to decrease the potential for complication. Since blood flow to the tumors is being reduced, it is common to have some abdominal discomfort and nausea after the procedure. These symptoms are most severe during the hours immediately after embolization and are usually significantly better by the next day. Pain and nausea medications are routinely provided to decrease the severity of these symptoms. Most patients go home the day after the procedure with pain and nausea medications, if needed, and with a several day supply of antibiotics to decrease the risk of infection.

Possible side effects of embolization include abdominal pain, fever, nausea, infection in the liver, gallbladder inflammation, and blood clots in the main blood vessels of the liver. Because healthy liver tissue can be affected, there is a risk that liver function will get worse after embolization. This risk is higher if a large branch of the hepatic artery is embolized. Serious complications are not common, but they are possible.
Radiation therapy

Radiation therapy is a cancer treatment that uses high-energy x-rays or other types of radiation from outside of the body to kill cancer cells or keep them from growing. Significant improvements have been made to radiation therapy in recent years. Some of the newer technologies include improved computer assisted treatment planning (smarter and faster and has more capability like auto-contouring), continuous imaging guidance, robotics, and higher dose rates — all with the goal of greater efficacy, less side effects and less time under treatment.

Before your radiation treatment begins, the radiation team will take careful measurements to determine the correct angles for aiming the radiation beams and the proper dose of radiation. Radiation therapy is like getting an x-ray but the radiation is much stronger. The procedure itself is painless with each treatment lasting only a few minutes. The setup time for the procedure — getting the tumor lined up for treatment — for the treatment, can take more time. Most often, radiation treatments are given 5 days a week for several weeks.

Radiation therapy is given in different ways:

- **External radiation therapy:** Uses a machine outside the body to send radiation toward the cancer. Three different types are:
  - **3-D conformal radiation therapy (3D-CRT):** Uses a computer to create a 3-D picture of the tumor. This allows doctors to give the highest possible dose of radiation to the tumor, while preventing damage to normal tissue as much as possible. This type of radiation therapy is being studied in clinical trials.
  - **Stereotactic body radiation therapy (SBRT):** Instead of giving small doses of radiation every day for several weeks, SBRT uses special equipment to position a patient and deliver high-dose radiation directly to the tumor on one or a few days. This type of radiation therapy is very targeted (to just a few millimeters, which helps prevent damage to normal tissue). To target the radiation precisely, the person is put into a specially designed body frame for each treatment.
  - **Proton-beam radiation therapy:** Is a type of high-energy radiation therapy that uses streams of protons (small, positively-charged particles of matter) to kill tumor cells.

Side effects of external radiation therapy can include skin changes (from redness to blistering and peeling), nausea and vomiting, fatigue and low blood counts. These side effects improve after treatment ends. Side effects tend to be more severe if radiation and chemotherapy are given together.

- An additional form of radiation therapy is called radioembolization. This process involves placing tiny glass or resin beads called “microspheres” into the blood vessels that are feeding your tumor. These beads, which are filled with the radioactive isotope yttrium (Y-90) block the supply of blood to the cancer cells. Once the beads are in place at the tumor site, they deliver this high dose of radiation (the Y-90) to the tumor and not the normal tissues.
Systemic Therapy (pills or intravenous)

Systemic targeted therapy is a treatment that uses drugs or other substances to identify and attack specific cancer cells without harming normal cells. Liver cancer may be treated with a targeted therapy drug that stops cells from dividing and prevents developing of new blood vessels that tumors need to grow. Targeted drugs work differently from other standard chemotherapy drugs and often have different and less severe side effects. Like standard chemotherapy, however, these targeted therapies work systemically, that is, they enter the bloodstream and reach all areas of the body, which makes them useful against cancers that have spread to distant organs.

One example of a targeted therapy for liver cancer is sorafenib, currently approved and available as a pill in the US. Sorafenib has been shown to inhibit cancer cell growth. This medicine will not completely cure liver cancer but may control the cancer from growing and increase the life span of people with this disease. Researchers are studying its use earlier in the course of liver cancer, often in combination with other kinds of treatment. It has not been studied much in people who already have poor liver function, so it is not known if it is safe for these people.

Sorafenib is taken twice daily as a pill. Sorafenib has side effects like other anticancer drugs including fatigue, high blood pressure, itching, dry or peeling skin, constipation, dry mouth, weight loss, abdominal pain, nausea, vomiting, diarrhea, rash, hair loss, loss of appetite and weakness, headache, redness, numbness, pain or blistering of hands or feet, rashes, and confusion. It can also increase risk of bleeding.
Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy for liver cancer is usually administered by inserting a needle into a vein. This type of chemotherapy is a systemic treatment because the drug enters the bloodstream, travels through the body, and can kill cancer cells outside the liver. In another type of chemotherapy called regional chemotherapy, a small pump containing drugs is placed in the body. The pump puts drugs directly into the blood vessels that are called arteries that go directly to the tumor.

Because some drugs work better together than alone, two or more drugs are often given at the same time. This is called combination chemotherapy. Other types of drugs may be used to treat your cancer. These may include certain drugs that can block or increase the effect of your body's response to the cancer.

Unfortunately, liver cancer resists most chemo drugs. The drugs that have been most effective as chemotherapy in liver cancer are doxorubicin (Adriamycin), 5-fluorouracil, and cisplatin. But even these drugs shrink only a small portion of tumors and the responses often do not last long. Even with combinations of drugs, chemotherapy has not helped patients live longer, in most studies.

FOR MORE INFORMATION

www.cancer.gov/cancertopics/wyntk/liver/page8
www.cancer.org/cancer/livercancer

Chemotherapy
The treatment of cancer with anticancer drugs. The main purpose of chemotherapy is to kill cancer cells. It usually is used to treat patients with cancer that has spread from the place in the body where it started (metastasized).

Systemic treatment
Therapy where drugs are delivered through an infusion in the bloodstream, travel through the body, and can kill cancer cells outside the liver at distant sites.

Combination chemotherapy
When two or more drugs are often given at the same time as anti-cancer therapy.
Alternative and Complementary Medicine

The usual treatments in cancer can be difficult to handle. When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn’t mentioned. Everyone, from friends and family, to internet groups and websites may offer ideas for what might help you. These methods can include vitamins, herbs, and special diets, or other methods such as massage or acupuncture.

What exactly are Complementary and Alternative Medicines (CAMs)?

Not everyone uses these terms the same way, and they are used to refer to many different methods, so it can be confusing.

Complementary treatments or methods are those treatments that are used along with your regular medical care. Alternative treatments or methods are used instead of a doctor’s medical treatment.

Complementary Treatment / methods:
Are not used to treat the cancer itself.
More research is needed to understand if these therapies are effective and how they work.

Alternative treatment / methods:
May be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may pose danger, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

If you’re thinking about using a complementary or alternative therapy, find out as much as you can about the therapy and talk to your healthcare team. It’s possible that the therapy might interfere with test results or regular medical care.

Complementary treatments
Complementary treatment methods are those treatments offered in addition to standard treatment options, not offered as cures for cancer. They are used to help you feel better. Examples include massage, meditation and acupuncture.

Alternative treatments
Alternative treatments may be offered as alternate treatments to those that are routinely accepted. Alternative treatments are typically offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may pose danger, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment.
Natural Products:

Antioxidants: Any substance (such as vitamin E, vitamin C, or beta-carotene) that reduces the damage caused by oxidation, such as the harm caused by free radicals.

Antioxidants are found in many foods, including fruits and vegetables. They are also available as dietary supplements. Examples of antioxidants include:

- Beta-carotene
- Lutein
- Lycopene
- Selenium
- Vitamin A
- Vitamin C
- Vitamin E

Vegetables and fruits are rich sources of antioxidants. There is good evidence that eating a diet with lots of vegetables and fruits is healthy and lowers risks of certain diseases. But it isn’t clear whether this is because of the antioxidants, something else in the foods, or other factors.

High-dose supplements of antioxidants may be linked to health risks in some cases. For example, high doses of beta-carotene may increase the risk of lung cancer in smokers. High doses of vitamin E may increase risks of prostate cancer and one type of stroke. Antioxidant supplements may also interact with some medicines. Because of this, be sure to tell your health care team about any antioxidants you use.
Herbs and Compounds:

A number of herbs and compounds have been found to be useful complementary therapies for people with liver cancer. They include:

**Astragalus root:** Found in China, only two of the over 2000 variations of the plant are used in healthcare settings. Several of the 2000 species of Astragalus not used in health care settings could be poisonous. While considered safe for most adults, its use may interfere with drugs that suppress the immune system. Blood sugar levels and blood pressure may also be affected.

**Chamomile:** The flowering tops of the plant have been used to help with digestion, anxiety and promote sleep. As a mouth rinse it is said to help with ulcers. Chamomile is well tolerated, however, if you are allergic to daisy plants you may also be allergic to chamomile.

**Curcumin:** The active ingredient in turmeric, a spice used in cooking and as a food coloring agent. Turmeric has been used to help digestion, liver function, and relieve arthritis. High doses or long term use of turmeric can cause indigestion, nausea, or diarrhea. If you have any gallbladder issues you should avoid turmeric, as symptoms may worsen.

**Licorice root:** Historically has been used for stomach ulcers, bronchitis, sore throats, and viruses, such as hepatitis. If used too much licorice root can cause serious side effects, especially in people with heart disease or high blood pressure.

**Resveratrol:** A compound found in grape skins, red wine, berries, and peanuts that acts as an antioxidant. Early research suggests resveratrol may prevent the growth of cancer cells, including liver cancer.

**Traditional Chinese Medicine (TCM):** TCM’s goal is to restore your body’s Qi (pronounced chee), the energy flow in your body essential for good health. Over 75 herbal compounds or mixtures have been identified as related to liver disease.
Mind/Body Practices:

Acupuncture: A key practice in traditional Chinese medicine, acupuncture is one of the oldest health customs in the world. The thinking behind acupuncture is that the life energy “Qi” (pronounced “chee”) flows along meridians—or pathways—throughout the body. Acupuncture helps open up blockages in those pathways. Although acupuncture encompasses a family of practices, the one most associated is the use of fine metal needles inserted in the skin along the meridians, then stimulated either manually or with electrical current. Acupuncture has been used to relieve chronic pain, and to help with a many different kinds of issues, from motion sickness to smoking cessation.

Acupressure: A similar practice to acupuncture in that it uses the handling (usually with fingers or hands) of various pressure points on specific areas of the body to allow the release of natural chemicals for healing. This is also known as “needleless acupuncture”. One positive of this treatment is that no special equipment is needed and you can be trained to self-administer treatment. Without training, however, acupressure can lead to pain, bruising, nerve damage and internal organ damage.

Massage: Is the act or art of treating the body by rubbing, kneading, patting, or the like, to stimulate circulation and relax the individual, physically and mentally. Many different forms of massage exist:

- **Swedish massage**: Most common type of body massage, uses long strokes, kneading, deep circular movements, vibration, and tapping
- **Deep tissue massage**: Used for long standing, deep muscular problems
- **Neuromuscular massage**: Used to balance the nervous system and the muscles
- **Shiatsu**: A Japanese form of bodywork, therapists use finger and palm pressure to restore balance in the body’s natural energy flow, or Qi
- **Aromatherapy massage**: The use of essential oils during massage to activate the limbic system, which helps controls emotions and influences the nervous system and hormones.
- **Reflexology**: Applied to points on the hands and feet with the aim of improving the health of other parts of the body

Research supports the use of massage to minimize anxiety, depression, and pain; and help regulate blood pressure and heart rate. Massage in most forms is safe. However, depending on where you are in your treatment journey, you may want to proceed with caution. If you are receiving chemotherapy or radiation therapy for your liver cancer it is recommended to work with a therapist trained in oncology massage.
Oncology massage training will make sure your therapist will not:

- Create lymphedema
- Mobilize a deep vein thrombosis (blood clot)
- Compromise your possible immunosuppressed state
- Send chemotherapy through your body more quickly than intended
- Over-tax your already exhausted body

**Meditation:** There are countless meditation techniques, some of which have been passed down through ancient traditions. Every technique has value; however, you don’t need any special tools to meditate. Meditation is claimed to calm the body and spirit; people who practice it routinely say it can provide peace of mind and clarity. All that is required during meditation is to sit still and enter into the quiet space in the mind that most people typically try to avoid by engaging in an endless stream of activities. Some of the meditation types include:

- **Mindfulness meditation:** Patients sit still in a comfortable position in a restful place. The idea is to gently keep bringing your mind back to the present moment whenever distractions or mind wandering occur.

- **Mindfulness based stress reduction (MBSR):** Normally a programmed event which teaches mindfulness meditation to help you cope better and be more at ease in your life. Often run through a clinic or hospital, it includes sitting meditation (breath awareness, focused attention), body scanning (awareness of sensations in the body), mindful movement, walking meditation and insight meditation.

- **Focused meditation:** This type of meditation involves focusing on something intently as a way of staying in the present moment and turning off your internal dialogue.

- **Visualization:** Creating specific images in your mind for specific reasons. For example, thinking of a Pac Man gobbling up cancer cells during treatment.

- **Guided meditation:** A teacher or recorded voice guiding a patient through a meditative process.

- **Transcendental meditation:** Repeating a specific word or phrase (mantra) to focus the mind, alleviate stress, and increase energy.

- **Prayerful meditation:** The aim is to expand spirituality: opening up to the idea of a higher being or developing positive qualities such as compassion and wisdom.
Reiki: With this treatment, Reiki (pronounced ray-kee) healers place their hands lightly or just above a person to balance energy and promote healing. This therapy was developed in Japan in the early 20th century. There is a debate as to the usefulness of Reiki, however, people receiving chemotherapy who also received Reiki report feeling more relaxed, with less stress and pain. As a treatment, Reiki appears safe and without side effects. There are three levels of training for Reiki practitioners (sometimes called “Reiki Masters”). Only those who have achieved the 2nd and 3rd level of training are allowed to charge for their services.

Tai Chi and Qi Gong: Both tai chi and qi gong are ancient Chinese energy therapies that use mind/body practices combining gentle physical movements, mental focus, and deep breathing. Both practices embrace the Chinese concepts of yin and yang (opposing forces within the body) and qi (a vital energy or life force). Both practices are generally safe, but muscle strain can occur with overuse. Do not do tai chi and qi gong immediately after eating.

Yoga: Yoga began in India over 5000 years ago as a system of relaxation, exercise and healing. Yoga combines breathing, stretching, postures and meditation. The belief is experiencing these four practices create harmony between your mind, body and spirit which help clear your mind of any stress or confusion. People with cancer who have done yoga report a sense of calm and better coping skills in dealing with their illness. They also said it helped with the side effects of their treatments (pain, being tired, sleep problems and depression).
A variety of factors can harm your liver and health. Risk reduction is taking action to lower one’s risk of developing cancer. The following risk reduction strategies may reduce the chance of developing liver cancer.

**Get treated for hepatitis infection**

If you have hepatitis infection (hepatitis B or C), get treated. If you do not know if you have hepatitis, get tested. Treatment of chronic hepatitis B infection can reduce the amount of virus in a person, which may lead to a lower risk of cirrhosis and liver cancer. Treatment of chronic hepatitis C infection these days has a good chance of eliminating the virus completely. Treating the virus may also lead to a lower risk of cirrhosis and developing liver cancer. However, many people do not know that they are infected with a hepatitis infection. People who are at high risk for developing hepatitis B and C, such as those who share needles, should be tested regularly so they can begin treatment if they are found to have either infection.

### The ABCs of Hepatitis

#### Hepatitis A

- **Caused by** the Hepatitis A virus (HAV)
- **Transmission**
  - Ingestion of fecal matter, even in microscopic amounts, from:
    - Close person-to-person contact with an infected person
    - Sexual contact with an infected person
    - Ingestion of contaminated food or drinks
- **Persons at Risk**
  - Travelers to regions with intermediate or high rates of Hepatitis A
  - Sex contacts of infected persons
  - Household members or caregivers of infected persons
  - Men who have sex with men
  - Users of certain illegal drugs (injection and non-injection)
  - Persons with clotting-factor disorders
- **U.S. Statistics**
  - Estimated 17,000 new infections in 2010

#### Hepatitis B

- **Caused by** the Hepatitis B virus (HBV)
- **Transmission**
  - Contact with infectious blood, semen, and other body fluids, primarily through:
    - Birth to an infected mother
    - Sexual contact with an infected person
    - Sharing of contaminated needles, syringes, or other injection drug equipment
  - Needlesticks or other sharp instrument injuries
- **Persons at Risk**
  - Infants born to infected mothers
  - Sex partners of infected persons
  - Persons with multiple sex partners
  - Persons with a sexually transmitted disease (STD)
  - Men who have sex with men
  - Injection drug users
  - Household contacts of infected persons
  - Healthcare and public safety workers exposed to blood on the job
  - Hemodialysis patients
  - Residents and staff of facilities for developmentally disabled persons
  - Travelers to regions with intermediate or high rates of Hepatitis B (HBsAg prevalence of ≥2%)
- **U.S. Statistics**
  - Estimated 38,000 new infections in 2010
  - Estimated 1.2 million people with chronic HBV infection

#### Hepatitis C

- **Caused by** the Hepatitis C virus (HCV)
- **Transmission**
  - Contact with blood of an infected person, primarily through:
    - Sharing of contaminated needles, syringes, or other injection drug equipment
    - Needlesticks or other sharp instrument injuries
- **Persons at Risk**
  - Infants born to infected mothers
  - Sex partners of infected persons
  - Needlestick or other sharp instrument injuries
  - Users of certain illegal drugs (injection and non-injection)
  - Persons with a sexually transmitted disease (STD)
  - Men who have sex with men
  - Household contacts of infected persons
  - Persons with known exposures to HCV (e.g., healthcare workers after needlesticks, recipients of blood or organs from a donor who later tested positive for HCV)
  - HIV-infected persons
  - Infants born to infected mothers
- **U.S. Statistics**
  - Estimated 17,000 new infections in 2010
  - Estimated 3.2 million people with chronic HCV infection

### Avoid alcohol

Drinking significant amounts of alcohol can cause cirrhosis of the liver. Cirrhosis increases the risk of developing liver cancer.

If you have hepatitis or other forms of liver disease, you may want to drink less alcohol or avoid it altogether.

If you choose to drink alcohol, limit the amount you drink:

- Men — less than 2 drinks a day
- Women — less than 1 drink a day

### Try to avoid smoking and/or avoid second-hand smoke

Smoking increases the risk of developing liver cancer. If you smoke, get help to quit. Your VA Care Team can recommend help you with a plan to quit.
opment of other liver diseases that can progress to cirrhosis, increasing the risk of developing liver cancer.

A healthy, well-balanced diet and regular exercise are two of the best ways to reach and keep a healthy body weight. People who are overweight or obese should avoid gaining any more weight and try to lose weight by eating healthier and exercising more. If you are overweight your VA Care Team can refer you to a nutritionist who can work with you to develop a diet that will help you lose those extra pounds.

Avoid exposure to harmful substances in the workplace
Workers in certain industries may be exposed to harmful substances, such as vinyl chloride and plutonium, which can increase the risk of developing liver cancer. Follow occupational health and safety standards if you work in an industry that processes, stores, transports or uses any cancer-causing substances.

Get treatment if you have a disease that increases the risk of liver cancer
In addition to hepatitis B and C, several diseases increase the risk of developing liver cancer. Treatment reduces damage to the liver caused by these diseases and reduces the risk of developing liver cancer.
Clinical Trials

What are clinical trials?

Clinical trials are research studies that involve people. They are the final step in a long process that begins with research in a lab. Most treatments that are used today are the result of past clinical trials.

Clinical trials are done to find out if new cancer treatments are safe and effective or better than the standard treatment. Clinical trials for liver cancer are designed to test new ways to:

- Treat liver cancer
- Find and diagnose liver cancer
- Manage symptoms of liver cancer or side effects from its treatment

Many of today’s standard treatments for cancer are based on earlier clinical trials. Patients who take part in a clinical trial may receive the standard treatment or be among the first to receive a new treatment.

Patients who take part in clinical trials also help improve the way cancer will be treated in the future. Even when clinical trials do not lead to effective new treatments, they often answer important questions and help move research forward.

Patients can enter clinical trials before, during, or after starting their cancer treatment.

Any time you or a loved one needs treatment for cancer, clinical trials are an option to think about. Trials are available for all stages of cancer. It is a myth that they are only for people who have advanced cancer that is not responding to treatment.

Why are clinical trials important?

Clinical trials are key to developing new methods to prevent, detect, and treat cancer. It is through clinical trials that researchers can determine whether new treatments are safe and effective and work better than current treatments. When you take part in a clinical trial, you add to our knowledge about cancer and help improve cancer care.

DID YOU KNOW?

Each year about 27,000 new patients enter into National Cancer Institute-sponsored clinical trials.
Who is in charge of a clinical trial?

Every clinical trial has a person in charge, usually a doctor, who is called the principal investigator. The principal investigator prepares a plan for the trial, called a protocol. The protocol explains what will be done during the trial. It also contains information that helps the doctor decide if this treatment is right for you. The protocol includes information about:

- The reason for doing the trial
- Who can join the trial (called “eligibility requirements”) or inclusion/exclusion criteria
- How many people are needed for the trial
- Any drugs that will be given, how they will be given, the dose, and how often
- What medical tests will be done and how often
- What types of information will be collected about the people taking part

Are there questions I should ask my doctor about treatment in clinical trials if I am thinking of participating in one?

If your doctor offers you a trial, here are some questions you may want to ask.

About this trial:

- What is the purpose of the trial?
- Why do the researchers believe that the treatment being studied may be better than the one being used now? Why may it not be better?
- How long will I be in the trial?
- What kinds of tests and treatments are involved?
- How will the doctor know if the treatment is working?
- When will I be told about the trial’s results?
- How long do I have to make up my mind about joining this trial?
- Who can I speak with about questions I have during and after the trial?
- Who will be in charge of my care?
- Is there someone I can talk to who has been in the trial?

Risks and Benefits:

- What are the possible side effects or risks of the new treatment?
- What are the possible benefits?
- How do the possible risks and benefits of this trial compare to those of the standard treatment?
Rights:
• How will my health information be kept private?
• What happens if I decide to leave the trial?

Costs:
• Will I have to pay for any of the treatments or tests?
• What costs will my health insurance cover?
• Who pays if I’m injured in the trial?
• Who can help answer any questions from my insurance company?

Daily life:
• How could the trial affect my daily life?
• How often will I have to come to the hospital or clinic?
• Will I have to stay in the hospital during the clinical trial? If so, how often and for how long?
• Will I have to travel long distances?
• Will I have check-ups after the trial?

Comparing choices:
• What are my other treatment choices, including standard treatments?
• How does the treatment I would receive in this trial compare with the other treatment choices?
• What will happen to my cancer without treatment?

How do I find out more about clinical trials for my liver cancer?
Your VA Care Team will let you know if there is a clinical trial that is right for you. More information about clinical trials can also be found at http://cancer.gov/clinicaltrials.
Is palliative care the same thing as hospice care?

No. Hospice care is an approach to care that handles medical, physical, emotional, social and spiritual needs for patients with advanced-stage disease, usually with six months or less to live. You can receive this care at home if your family is around and is able and ready to help out with your needs. The hospice team consults regularly with your doctor or nurse practitioner. If needed, you may have a home health aide to assist you for a few hours every day for things like bathing. You may also receive hospice care in a facility. You are entitled to hospice care if you and your doctor agree not to pursue active care such as chemotherapy. Some hospice programs allow Nexavar. You may need hospice care if your condition worsens.

What kind of special arrangements are needed with advanced care?

You may want to consider putting special proxies in place. If Advance Directives have not yet been put in place they should be arranged. In addition you may want to put a financial proxy or power of attorney in place, which gives someone you trust the authority to handle financial transactions on your behalf. This person (or “agent”) can handle things as simple as sorting your mail and depositing Social Security checks to more complex as reviewing your retirement accounts and other investments. Your agent can be a loved one or family friend or a financial professional.

Your financial power of attorney ends if:

- You revoke it. As long as you are mentally competent, you can revoke a financial power of attorney at any time
- At the time of your death. That means you cannot give your agent authority to handle things after your death, such as paying your debts, making funeral arrangements or transferring property to the people who inherit it. If you want your agent to handle your affairs after your death, use a will to name that person as your executor.
- No agent is available. To avoid this you can name an alternate agent in the document.

FOR MORE INFORMATION

**Ablation therapy:** Ablation therapy is a type of minimally invasive procedure used to remove abnormal liver tissue using heat (radiofrequency ablation, RFA), extreme cold (cryoablation), lasers or chemicals.

**Acupressure:** Acupressure is a form of touch therapy that utilizes the principles of acupuncture and Chinese medicine. In acupressure, the same points on the body are used as in acupuncture, but are stimulated with finger pressure instead of with the insertion of needles. Acupressure is used to relieve a variety of symptoms and pain.

**Acupuncture:** The practice of inserting thin needles into the body at specific points to relieve pain, treat a disease, or anesthetize a body part during surgery. Acupuncture has its origin in traditional Chinese medicine and has been in use for more than 5,000 years.

**Advanced Directives:** Advanced directives are legal documents that allow people to communicate their decisions about medical care to family, friends, and health care professionals in the event that they are unable to make those decisions themselves—for example, due to being unconscious or in a coma.

**Aflatoxin:** A toxin produced by Aspergillus flavus and A. parasiticus, molds which contaminate ground nut seedlings; it has been implicated as a cause of hepatic carcinoma in humans.

**Alanine Aminotransferase (ALT):** ALT is normally found largely in the liver. It is not found only in the liver, but that is where it is most concentrated. It is released into the bloodstream as the result of liver injury. Thus, it serves as a fairly specific indicator of liver status. A normal ALT in adults is 7 to 40.

**Albumin:** Albumin is a very common protein found in the blood with a variety of functions. It also is produced only in the liver, and if its levels are lower than normal it can be suggestive of chronic liver disease or liver cirrhosis. Many conditions other than liver disease also may cause low albumin levels. Normal values are about 3.5 to 5.0

**Alpha-fetoprotein (AFP):** A protein found at an elevated level in the blood of adults having certain malignancies. AFP measurements in amniotic fluid are used for the early diagnosis of fetal neural tube defects, such as spina bifida and anencephaly. Elevated serum levels may be present in ataxia-telangiectasia syndrome, hereditary tyrosinemia, cirrhosis, alcoholic hepatitis, hepatocellular carcinoma, and viral hepatitis. Although not a specific genetic marker for malignancies, AFP may be used to monitor the effectiveness of surgical and chemotherapeutic management of hepatomas and germ cell neoplasms.

**Alternative treatments:** Alternative treatments may be offered as alternate treatments to those that are routinely accepted. Alternative treatments are typically offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may pose danger, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment.

**Antioxidants:** Any substance (such as vitamin E, vitamin C, or beta-carotene) that reduces the damage caused by oxidation, such as the harm caused by free radicals.

**Arterial embolization:** Also known as trans-arterial embolization (or TAE), a procedure where a thin, flexible tube (known as a catheter) is put into an artery through a small cut in the inner thigh and threaded up to the hepatic artery in the liver. Once the catheter is in place, small particles are injected into the artery to plug it up.

**Ascites:** an abnormal buildup of fluid in the abdomen.
Aspartate Aminotransferase (AST): This enzyme is normally found in a variety of tissues including liver, heart, muscle, kidney, and brain. It is released into the serum when any one of these tissues is damaged. For example, AST level in serum is elevated in heart attacks or with muscle injury. A normal AST in adults is 5 to 40.

Astragalus root: An herb common in traditional Chinese medicine, has been used as an immune system booster, for chronic hepatitis, for colds and respiratory infections. While considered safe for most adults, its use may interfere with drugs that suppress the immune system.

Autoimmune hepatitis: A chronic disease in which the body’s immune system attacks the normal cells of the liver and causes liver damage like cirrhosis and liver failure.

Barcelona Clinic Liver Cancer (BCLC) Staging System: A staging system used in HCC.

Benign tumor: A tumor that is a growth of noncancerous cells; not malignant.

Bile: A substance produced by the liver, and concentrated and stored in the gallbladder. Bile contains many different substances, including bile salts, cholesterol, and bilirubin. After a meal, the gallbladder pumps bile into the first part of the small intestine to keep the intestine’s contents at the appropriate pH for digestion, and to help break down fats.

Bilirubin (Bili): Bilirubin is the end result of the routine destruction of red blood cells occurring in the liver. It is usually released as bile in the stool. When bilirubin is elevated it can suggest liver dysfunction. A normal bilirubin is 0.1 to 1.0.

Biopsy: The removal of tissue from the body, typically with a hollow needle, and examination, usually with a microscope, performed to establish a precise diagnosis.

Chamomile: The flowering tops of the plant have been used to help with digestion, anxiety and promote sleep. As a mouth rinse it is said to help with ulcers. Chamomile is well tolerated, however, if you are allergic to daisy plants you may also be allergic to chamomile.

Chemoembolization: Also known as trans-arterial chemoembolization (or TACE), a procedure that combines embolization with chemotherapy. This is most often done either by using tiny beads that give off a chemotherapy drug for the embolization.

Chemotherapy: The treatment of cancer with anticancer drugs. The main purpose of chemotherapy is to kill cancer cells. It usually is used to treat patients with liver cancer that has spread from the place in the body where it started (metastasized). Chemotherapy destroys cancer cells anywhere in the body.

Child-Pugh Score: A score that measures liver function, especially in people with cirrhosis. Many people with liver cancer also have cirrhosis, and in order to treat the cancer, doctors need to know how well the liver is working.

Clinical Trials: Highly regulated and carefully controlled patient studies, where new drugs to treat cancer and/or novel methods of treatment are investigated.

Curcumin: A chemical extract from the food spice turmeric, has been used to help digestion and liver function and relieve arthritis.

Cirrhosis: A state of damage to the liver when enough of the healthy liver cells have been replaced by fibrosis or scar tissue.
**Combination chemotherapy:** When two or more drugs are often given at the same time as anti-cancer therapy.

**Complementary treatments:** Complementary treatment methods are those treatments offered in addition to standard treatment options, not offered as cures for cancer. They are used to help you feel better. Examples include massage, meditation and acupuncture.

**Computed tomography (CT) scan:** A technology that uses computer-processed x-rays to produce images (virtual ‘slices’) of specific areas of the scanned object, allowing the medical provider to see what is “inside” without cutting the patient open.

**Embolization therapy:** A procedure that injects substances to try to block or reduce the blood flow to cancer cells in the liver.

**Financial proxy:** Also known as a durable power of attorney, a legal document that authorizes someone (an “agent”) to make financial transactions on your behalf. These transactions can range from depositing checks to managing your investments.

**Health Care Proxy:** A document that allows a patient to appoint someone to make health care decisions in the event that they are not able to do so. Once the document is drafted, the primary individual continues to be allowed to make health care decisions as long as they are still able to do so.

**Hemoglobin:** The part of a red blood cell that carries oxygen to the tissues. Normal levels for an adult male are 14 to 18 and 12 to 16 for an adult female. If your count is below 8, a transfusion may be considered.

**Hepatectomy:** Surgical removal of all or part of the liver.

**Hepatic arterial infusion therapy (HAI):** A chemotherapy approach where chemotherapy drugs are put directly into the hepatic artery (HAI).

**Hepatocellular carcinoma:** Cancer of the liver, also known as HCC.

**Hepatocytes:** Liver cells

**Hepatologist:** A doctor who specializes in diseases of the liver.

**Hospice care:** Hospice is an approach to care that handles medical, physical, emotional, social and spiritual needs for patients with advanced-stage disease, usually with six months or less to live.

**Infectious Disease Doctor:** A doctor who specializes in taking care of patients with infections. These infections can be caused either by bacteria or viruses.

**Interventional radiologist:** A doctor (radiologist) who utilizes minimally-invasive image-guided procedures to diagnose and treat diseases in nearly every organ system. The goal of interventional radiology is to diagnose and treat patients using the least invasive technique currently available in order to minimize risk to the patient and improve their health.

**Jaundice:** A yellowish pigmentation of the skin, the whites of the eye and other mucous membranes caused by increased bilirubin in the blood

**Joint survivorship agreement:** A legal document in which spouses may agree between themselves that all or part of their property, then existing or to be acquired, becomes the property of the surviving spouse on the death of a spouse.
Laparoscopic liver biopsy: This is where a special instrument known as a laparoscope, which allows doctors to view the liver, is inserted through a small cut in your abdomen. The laparoscope is a small tube with a camera on the end. The doctor will use instruments attached to the laparoscope to remove tissue samples from your liver. This technique is useful when the doctor wants to take a biopsy from a specific part of the liver. This is the least common type of liver biopsy.

Licorice root: An herb historically used for stomach ulcers, bronchitis, sore throats, and viruses, such as hepatitis.

Liver transplant: An operation that replaces the liver with a portion of a liver (from a living donor) or an entire liver (from a deceased donor).

Lymphedema: Swelling caused by the inability of lymph fluid to escape an area of your body. Lymph is what carries cellular waste until it can be filtered and disposed of, either by the lymph nodes or in the kidneys. Lymphedema is not life threatening, but it is inconvenient, can be painful, and can progress to cause more serious problems.

Malignant hepatoma: Also known as hepatocellular carcinoma (HCC), the type of cancer that starts in the liver.

Magnetic resonance imaging (MRI): A medical imaging technique (x-ray) used to visualize internal structures of the body in detail. MRI can create more detailed images of the human body than are possible with X-ray, especially cross-sectional images.

Massage: The rubbing and kneading of superficial and deeper layers of muscle and connective tissue using various techniques, to aid in the healing process, and promote relaxation and well-being.

Meditation: A broad variety of practices that includes techniques designed to promote relaxation, calm the body and spirit, and provide peace of mind and clarity.

MELD Score: A scoring system for assessing the severity of chronic liver disease.

Metastasis: The development of secondary malignant growths at a distance from a primary site of cancer.

Milan Criteria: Eligibility criteria used in liver transplant.

Milk thistle: An herb said to protect and promote liver cell growth, act as an antioxidant and prevent inflammation.

Neutrophil: It is the most important type of WBC in fighting infection. You are at higher risk of infection when this number is below 1000. A normal count is 2500 to 7000. A count below 1000 is called neutropenia.

Nurse: A professional caregiver working usually in conjunction with a doctor or nurse practitioner that provides healthcare. Nurses work in a wide variety of settings including medical offices, clinics, and home healthcare, to name just a few.

Nurse manager/coordinator: A member of the health care team that helps with appointments and scheduling procedures.

Nurse Practitioner: A registered nurse with a graduate degree in advanced practice nursing that can diagnose and treat minor illnesses and perform routine procedures.

Nutritionist: A person who advises on matters of food and nutrition impacts on health. Also known as a dietitian.
**Oncologic Surgeon:** A surgeon who treats cancer by operating on patients and removing tumors via surgery.

**Oncologist:** A doctor who specializes in cancer.

**Palliative care:** An area of healthcare that focuses on relieving and preventing the suffering of patients. Palliative care is appropriate for patients at all disease stages.

**Palliative Care Physician:** A doctor who specializes on relieving the pain and other draining symptoms of serious and chronic illness.

**Paracentesis:** Removal of the fluid from the peritoneal cavity.

**Partial hepatectomy:** Surgery to remove the cancerous portion of a liver.

**Percutaneous liver biopsy:** A procedure in which a long needle is introduced through the skin of your chest or abdomen. The needle removes 2 or 3 small samples of liver tissue. This procedure is usually performed on an outpatient basis. If you have a history of bleeding problems your doctor may want to perform a transjugular biopsy.

**Peritoneal cavity:** The space between the internal organs and the wall of the abdomen.

**Pharmacist:** The individual on the team trained to dispense medicines and give advice on the best way to take them. Pharmacists are a great resource of information about the medicines you are taking, how they may interact with food, other medicines and the best time of day to take them.

**Platelet:** A blood cell that is involved in blood clotting. When this count is below 50,000, you are at higher risk of bleeding. The risk of bleeding increases as the count becomes lower. A normal count is 150,000 to 300,000 in an adult. If your count is below 10,000 a transfusion is considered.

**Primary Care Physician (PCP):** A doctor who is the first point of contact and manages the overall care and health of patients. This doctor refers patients to other specialists as needed.

**Principal Investigator:** A doctor who is in charge of a clinical trial.

**Protocol:** The specific plan and details of a clinical trial that describes each step, the specific types of patients who are eligible to enroll and how the study is to be conducted.

**Qi:** In traditional Chinese medicine, the vital force which is believed to flow through the body along routes known as meridians. Illness is attributed to changes in the flow of qi which, according to the construct of Chinese medicine, can be treated by placing needles (acupuncture) or pressure (acupressure) at specific points on the meridians.

**Radiation Oncologist:** A doctor who specializes in the treatment of cancer using radiation therapy.

**Radiation therapy:** A common form of cancer therapy used to kill or damage cancer cells through the use of radiation.

**Radioembolization:** Also known as RE, combines embolization with radiation therapy. This is done by injecting small radioactive beads into the hepatic artery.

**Radiologist:** A doctor trained in radiology (x-ray) interpretation and its use in the diagnosis of diseases and injuries.

**Reiki:** A form of therapy that uses simple hands-on, no-touch, and visualization techniques, with the goal of improving the flow of life energy in a person.
**Resection (partial):** An operation to remove a section of liver that is cancerous.

**Resveratrol:** A compound found in grape skins, red wine, berries, and peanuts that acts as an antioxidant.

**Risk factors:** Anything that increases your chance of getting a disease.

**Social Worker:** A social worker is the person on the team supporting efforts to obtain community services and resources, a link to counselling and family treatment and cancer.

**Systemic targeted therapy:** Therapy where drugs are delivered through an infusion in the bloodstream, travel through the body, and can kill cancer cells outside the liver at distant sites.

**Tai Chi:** A Chinese exercise system that uses slow, smooth body movements to achieve a state of relaxation of both body and mind.

**Targeted therapy:** A broad term for therapies that impact on a specific molecular pathway or target.

**TNM System:** A staging system for liver cancer based on tumor size, node involvement and if metastasis has occurred.

**Traditional Chinese Medicine (TCM):** An ancient and still very vital holistic system of health and healing, based on the notion of harmony and balance, and employing the ideas of moderation and prevention. TCM utilizes complimentary methods including herbs, exercise and monitoring the Qi.

**Transjugular liver biopsy:** A transjugular liver biopsy is often advised for people who have a problem with blood clotting or a large amount of fluid in their abdomen. It is done by an interventional radiologist, a doctor who specializes in this type of procedure. During a transjugular biopsy your doctor will insert a small tube into your jugular (neck) vein. X-rays will help guide the tube into a large vein in your liver. A small needle is inserted through the tube and into your liver. The needle removes 2 or 3 small samples of tissue.

**Tumor Board:** A meeting of experts where the diagnosis, options for treatment and next steps for patients with cancers are reviewed and discussed.

**Ultrasound:** Sound or other vibrations having an ultrasonic frequency, particularly as used in medical imaging.

**Varices:** A dilated vein in the linings of the esophagus and upper stomach when these veins fill with blood and swell due to an increase in blood pressure in the portal veins.

**VISN Liver Cancer Coordinator:** The person on the VA Care Team that assists with coordinating your care across the many disciplines (x-ray, imaging, oncology etc.).

**White blood cells (WBC):** Produced in the bone marrow and part of the body’s immune system, helping to fight infection. A normal WBC count is 4,000 to 11,000 in adults

**Yoga:** A system of relaxation, exercise and healing that combines breathing, stretching, postures and meditation. The belief is experiencing these four practices create harmony between your mind, body and spirit which help clear your mind of any stress or confusion.
As a caregiver for a friend, family or loved one, your role as support system is important. Your loved one will look to you to help accompany them to appointments, help with taking notes and also to ask questions you may not think of.

**Talking About Advance Directives**

It can be very hard to think about a time when your family member will need a health care proxy (a time when he or she will not be able to make decisions). It is also hard, or impossible, to predict what types of decisions will need to be made. That is why it helps to talk now about your family member’s health care choices.

Sometimes the hardest part of this conversation is getting started. You can stress that it is important that you know what your family member wants so that you can speak for him or her if it becomes necessary. Ask your family member’s social worker or other health professional if you want help talking about advance directives.

Now is a good time for your family member to complete the Health Care Proxy if he or she does not already have one. As the family caregiver, it is also a good time to complete your own Health Care Proxy. Doing this can help ensure that your medical choices are respected and followed.

**Advance Directive Information**

Advance Directives are written documents that tell others, especially health care professionals which medical treatments people do or do not want. These may include the use of a ventilator (breathing machine), artificial feeding (tube through the stomach), and other types of medical treatments. Advance directives become effective only when the person cannot speak for him- or her-self. This may be because the person is too ill or mentally unable to make decisions. Advance directives cover two basic kinds of information:

- The kinds of treatments that your family member does or does not want.
- Name the person who can make health care decisions if your closest family member is not able to do so.
Here are the most common forms of advance directives:

- **Health Care Proxy**: A form that allows a person to name someone else—a called a health care agent or a surrogate (substitute)—to make health care decisions on his or her behalf. This is done by completing a Health Care Proxy form. Each state has its own laws and regulations regarding surrogate decision makers. You can contact your state’s Department of Health to find out the laws and forms that apply in your state.

- **Living will**: A living will is a written description of what kind of medical treatments a person would or would not want in the future. The living will and written instructions on the Health Care Proxy form have similar goals, but the State-approved form is likely to carry more weight with health care professionals.

- **Financial proxy**: A financial proxy is also known as a durable power of attorney, a legal document that authorizes someone (an “agent”) to make financial transactions on your loved one’s behalf. These transactions can range from depositing checks to managing your investments. A financial proxy can be revoked or remain in effect from the time they are no longer able to make financial decisions for themselves to their passing. A financial proxy does not remain in effect after death. An individual or agent needs to be named an Executor in a will or other legal document to handle financial transactions after someone is deceased.

- **Do Not Resuscitate (DNR) order**: DNR allows a person to make a health care choice about one specific treatment. It is used when people stop breathing or their heart stops. The DNR tells the health care team that the patient does not want cardiopulmonary resuscitation (also called “CPR”) which means trying to restart the heartbeat.

**DID YOU KNOW?**

A Health Care Proxy Form is not transferable from one state to another. You need to have a valid form for the state your family member resides at, or multiple forms, if he or she resides or spends time in several states.
Here are some facts to know about the DNR:

- The DNR order must be signed by a doctor.
- As a family caregiver, you may also be asked to sign the order.
- The DNR is valid even if there is no health care proxy.
- If a DNR order was signed in one facility, for example a hospital, it does not automatically mean it will be valid in another. You need to find out whether a new DNR order needs to be signed or if the existing order can be transferred and how.

There is a special type of DNR to be used at home, called an Out-of-Hospital DNR Order. This tells emergency personnel not to perform CPR if your family member’s heart stops when at home. The Out-of-Hospital DNR Order must be signed by a doctor.

Several states have POLST (Physician Orders for Life-Sustaining Treatment) forms that allow for DNR and other orders to be followed when patients are transferred from one health care setting to another and at home. In New York State, for example, the document is called MOLST (Medical Orders for Life-Sustaining Treatment). Check with your local VA Care Team about this.

### Managing Treatment Care

The development of a comprehensive End of Treatment Care plan for a patient and family that weaves all of the required and important parts and pieces together is a very valuable piece of the treatment journey. Creating this End of Treatment Care plan that includes the various disciplines (physician, nursing, social work, home health care worker, chaplain, family care givers etc.) provides reassurance of having a detailed action plan for the path forward. This plan includes details around prescriptions (dosing, how best to communicate with pharmacies), equipment (who owns the equipment, date ordered, payer) as well as more typical physician orders for clinical care.
Hospice Care

If your loved one’s condition is determined to be terminal they may qualify for hospice care. Hospice supports both you and your loved one with honor and dignity providing comfort and care during the end of life. Hospice care helps those with limited life expectancy by providing:

- Pain and symptom management
- Social, spiritual and emotional support to you and your loved one
- Medication, supplies and equipment related to the liver cancer
- 24 hour on-call support
- Respite care, giving you time away from care giving
- An individualized plan of care that meets the needs of both your loved one and you as a care giver
- Bereavement services for your family members

Hospice care is provided by a team that includes physicians, nurses, social workers, home health aides, chaplains and trained volunteers. Several options exist for payment for services:

- Enrollment in a VA health system
- Medicare or Medicaid
- Private insurance plans

Options also exist for where the care is provided, including:

- The home of the veteran of caregiver
- Senior housing
- Assisting living and long-term care facilities
- Group homes, residences and foster care
- Community nursing homes
- Community Hospitals
- VA Community Living Centers
- VA Medical Centers

A member of your loved one’s Care Team can provide the best guidance on how to manage this very important phase of care for your loved one and your family.

FOR MORE INFORMATION

www.atlanta.va.gov/services/Hospice.asp
Website References:

Below are a list of websites that may be a useful resource for you and your family as you experience liver disease.

FOR MORE INFORMATION

www.atlanta.va.gov/services/Hospice.asp
dashdiet.org/what_is_the_dash_diet.asp
news.cancerconnect.com/massage-therapy-and-cancer/
nccam.nih.gov/health
www.cancerresearchuk.org/cancer-help/about-cancer/treatment/complementary-alternative/therapies/
www.fda.gov/food/dietarysupplements/
www.hopkinsmedicine.org/liver_tumor_center/treatments/palliative_care.html
www.mayoclinic.org/diseases-conditions/liver-cancer/basics/symptoms/con-20025222
www.rocketswag.com/medicine/senior-care/hospice-care/Hospice-Care-For-Liver-Cancer.html
www.aasld.org/patients/Pages/default.aspx
www.cdc.gov/
My Daily Planner

During the course of your treatment it is important to keep track of your appointments, medications, treatments, and lab results. Use this section as an aid in your care, along with your VA Care Team.

People also find keeping a diary very helpful as a way of tracking symptoms, their feelings, and questions. You may want to have a separate journal as a diary. You can use the space below to keep notes of important issues or questions for your doctors and nurses.

NOTES

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My Daily Planner

Appointment List

It is easy to get overwhelmed by the number of appointments scheduled for your care by the VA Care Team. Keeping an appointment list is one way to make sure you don’t miss any of your scheduled visits. Add your next visit to the list before you leave your physician’s office. Use the Diary / Notes section to write down any questions or important information you want to discuss at that visit. (Copyright © 1994-2011 Trustees of the University of Pennsylvania, www.oncolink.org)

<table>
<thead>
<tr>
<th>Physician Name/ Specialty</th>
<th>Location, Date and Time Next Appointment</th>
<th>Notes</th>
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Medication List

It is important to keep a list of all medications you are taking (including vitamins and supplements). Keep a copy in your treatment binder and one in your wallet or purse. It will be helpful to be able to update it at doctor’s visits and to have on hand when seeing a new physician or going to an emergency room. Draw a line through a medication when it is stopped and note why in the last column. List any allergies below.

Allergies:

<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>Dose</th>
<th>When to Take</th>
<th>Who Prescribed</th>
<th>Date Started</th>
<th>Reason for Taking, Changing or Stopping</th>
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**Chemo Record**

Keep a record of the cancer treatments you receive. You may want to include supportive medications like growth factors and anti-nausea meds and make note of how they helped/didn’t help you. If you can keep track of the doses, it will be easier to access this information in the future. Make note if a dose needs to be adjusted and why, any major side effects and who prescribed the medication.

<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>Dose and Route (oral, IV)</th>
<th>Date Received</th>
<th>Who Prescribed</th>
<th>Side Effects, Dose Changes, Comments</th>
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**Radiation Therapy Record**

The amount of radiation therapy given is restricted over a person’s lifetime. It is important that your radiation oncologist is aware of any radiation that may have been delivered in the past. Keep a record of when you are treated, location on the body treated, total dose delivered, and the name of the radiation oncologist responsible for delivering the treatments.

**Radiation Therapy Treatment Plan**

<table>
<thead>
<tr>
<th>Radiation oncologist:</th>
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<tbody>
<tr>
<td>Contact information:</td>
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<td>Address</td>
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<td>Phone</td>
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<tr>
<td>Facility where treatment was done:</td>
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<tr>
<td>Type of radiation therapy:</td>
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<tr>
<td>Area in the treatment field:</td>
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<td>Total planned dose:</td>
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<td>Total number of planned sessions:</td>
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<td>Date therapy stated:</td>
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<tr>
<td>Date therapy completed:</td>
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<tr>
<td>Total dose received:</td>
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</table>

**Notable side effects:**
Radiology and Diagnostic Test Record

Keep a record of any radiology studies or diagnostic tests, such as MRI, CT scan, liver biopsy, etc. Keep track of where and when the test was done and a short description of the results. When having radiology tests, ask for a copy of the films on CD to keep in your binder—many physicians like to look at them in addition to the report and it will save you an additional trip. There is a pocket in the back of your binder to keep the result reports and scans on CD handy.

<table>
<thead>
<tr>
<th>Test or Study</th>
<th>Date</th>
<th>Facility Where Performed</th>
<th>Physician</th>
<th>Results</th>
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**Blood Count Record**

Use the blood count chart to follow your blood counts after treatment. This will help you know when extra precautions are necessary. Use the treatment column to record days you received chemotherapy, biologics or radiation therapy and any types of blood transfusions you may receive.

<table>
<thead>
<tr>
<th>Date</th>
<th>WBC</th>
<th>Neutrophil</th>
<th>Hemoglobin</th>
<th>Platelets</th>
<th>Treatment / Comments</th>
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Liver Function Test Record

Use the liver function test chart to follow your lab tests over the course of your treatment. This will help you organize your lab tests in one place over the course of your therapy.

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