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3rd Edition

LIVER CANCER

*A Treatment Guide for
Patients and their Families*



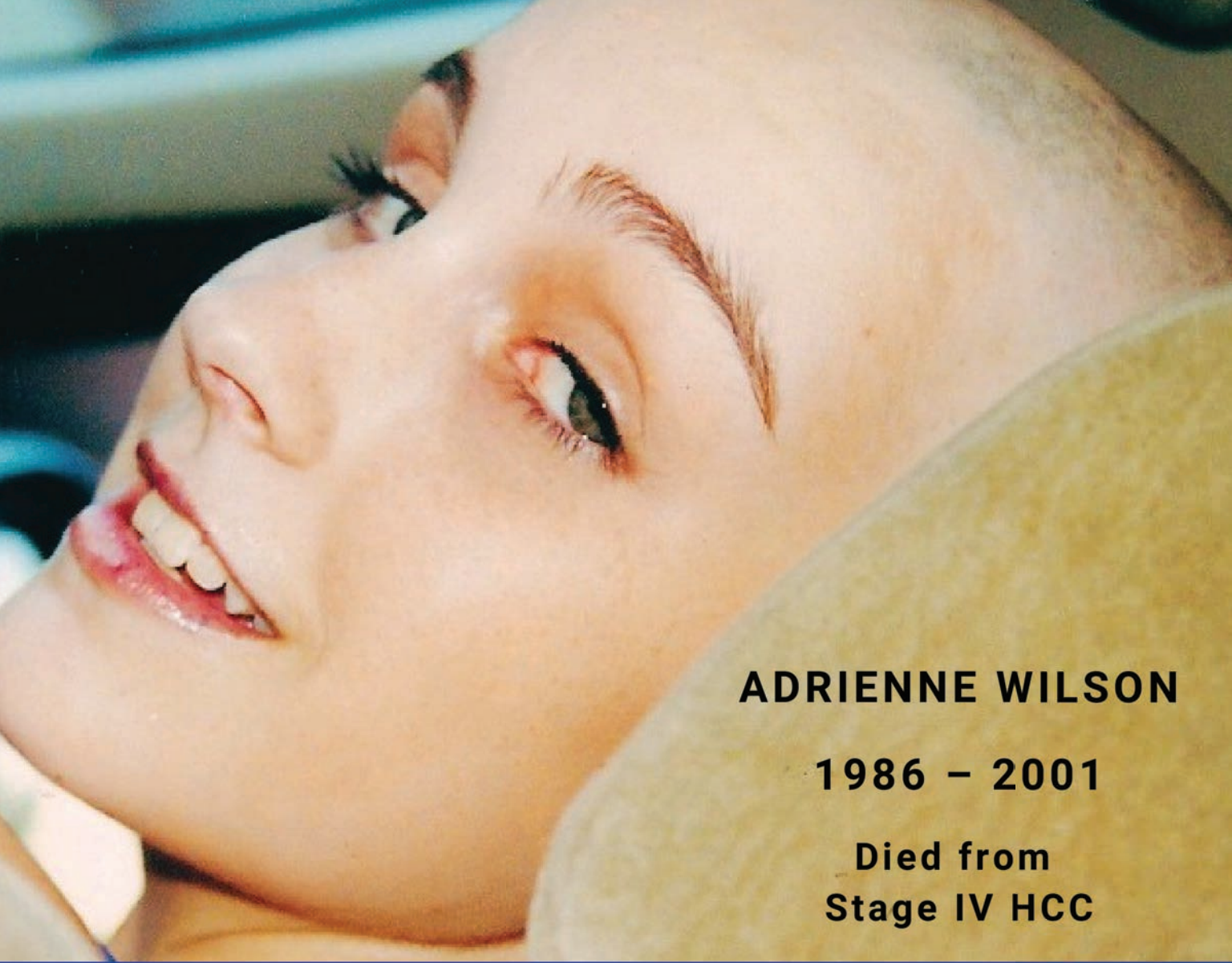
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ADRIENNE WILSON

1986 – 2001

**Died from
Stage IV HCC**

fighting liver cancer together

BLUE FAERY

Our mission is to prevent, treat and cure primary liver cancer, specifically Hepatocellular Carcinoma (HCC) through research, education and advocacy.

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LIVER CANCER



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A strong network offers confidence and strength

Rceiving a liver cancer diagnosis is understandably troubling because, simply put, you cannot live without your liver. It is indispensable to your body, which makes it critical that you surround yourself with the best medical team and support system available. It may comfort you to know that new drugs, treatment strategies and clinical trials are making great strides in liver cancer treatment.

Primary liver cancer is a disease in which cancer cells form in the tissues of the liver. Cancer that develops in other parts of the body and metastasizes (spreads) to the liver is not primary liver cancer. It is considered the type of cancer from where it originated and is treated as such.

Liver cancer is a disease of the hepatobiliary (heh-PAH-toh-BIH-lee-ayr-ee) system. “Hepato” means liver, and “biliary” refers to the gallbladder and bile ducts. The two main types of primary liver cancer are hepatocellular carcinoma (HCC) and cholangiocarcinoma (also called bile duct cancer). Other types include angiosarcoma, a rare, aggressive form, and hepatoblastoma, the most common type of childhood liver cancer, usually affecting children 3 years or younger.

This guide offers information about HCC, the most common type of liver cancer.

UNDERSTANDING HCC

HCC begins in the hepatocellular cells of the liver tissue. You may hear it referred to as a disease within a disease because it is usually found in the presence of an underlying chronic liver condition. This makes it challenging to diagnose and treat. Less frequently, HCC can develop in an otherwise healthy liver.

The most common underlying condition of HCC is cirrhosis, which is scarring of the liver. Cirrhosis is a chronic, progressive disease that causes inflammation and irreversible damage as scar tissue slowly replaces healthy liver cells and the organ gradually loses function.

Another condition that is on the rise is nonalcoholic fatty liver disease (NAFLD), and its most severe form, nonalcoholic steatohepatitis (NASH), can also cause cirrhosis (see NASH, page 3).

Viral hepatitis B and C, which are carried and spread through contact with blood and other bodily fluids, are also potential underlying conditions.

Higher incidence rates of HCC are found in people over the age of 60 and in Asians

and Pacific Islanders, African Americans, Hispanics and American Indians/Alaska Natives. Although age and ethnicity are out of your control, you can make certain lifestyle changes related to diet, exercise, hepatitis B vaccinations and hepatitis C treatment that may reduce your chance of underlying conditions contributing to a liver cancer diagnosis.

The vast majority of patients do not feel symptoms related to HCC, but some that may rarely occur include the following:

- Bloating
- Decreased appetite
- Deep fatigue
- Feeling full despite eating less than normal
- Mild to moderate pain or tenderness in the upper right part of the abdomen or right shoulder
- Unintended weight loss
- Vomiting

When HCC becomes advanced and spreads beyond the liver (most commonly to the lung, abdominal lymph nodes or bone), multiple tumors may develop simultaneously and these symptoms may occur:

- Ascites (uh-SY-teez), swelling in the abdomen or legs
- Dark urine

- Light-colored stools
- Jaundice, causing yellow skin and yellowing in the whites of the eyes

NEXT STEPS

Once you receive an HCC diagnosis, you are encouraged to find a doctor or cancer center with extensive experience treating it. The team approach is important because you typically have two conditions to manage: HCC and underlying liver disease. Experts on your team will accurately diagnose and stage the cancer, plan effective treatment, address the underlying condition and coordinate supportive care to help manage side effects (see *Supportive Care*, page 12). If you do not have access to an expert, seek a second opinion or ask your doctor to connect you with an expert for a consultation.

Another component of an HCC diagnosis is something you, your loved ones and caregivers may encounter known as disease stigma. It often accompanies HCC diagnoses because of the associated underlying conditions of the disease that may be related to lifestyle choices. It can make you feel embarrassed or ashamed, causing you to withdraw from friends, family and even medical appointments.

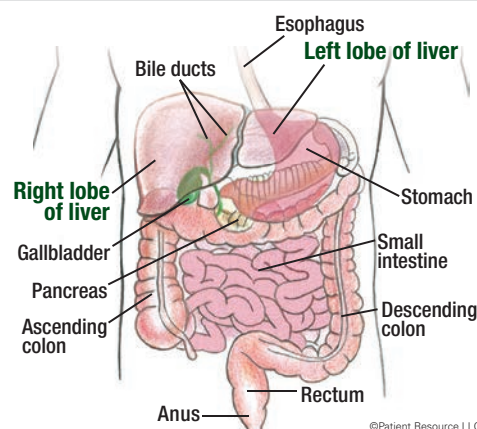
Most cancer centers and hospitals employ supportive care specialists who can address disease stigma along with other emotional, practical and spiritual aspects of your diagnosis. Advocacy and support groups can offer additional resources and can connect you with other people who are facing HCC. No one should have feelings of guilt about cancer, regardless of lifestyle choices. ■

ANATOMY OF THE ABDOMEN

The liver is the largest organ in the body. It has two lobes and is located on the upper right side of the abdomen above the stomach, protected by the ribs.

Along with playing a key role in the digestion of food, the liver performs more than 500 functions.

The liver is the only organ in the body with the ability to regenerate itself, which means that when part of the liver is removed, as long as the remaining part of it is healthy, it has the ability to grow back. However, a liver afflicted with a chronic disease such as cirrhosis cannot regrow. This may limit surgical options for cancer treatment.



Education is the best prevention

Nonalcoholic steatohepatitis (NASH) is a serious liver condition characterized by inflammation and scar tissue (fibrosis). It is the most severe form of nonalcoholic fatty liver disease (NAFLD), and it is not related to significant alcohol consumption.

Long term, it can progress to a more severe form of fibrosis called cirrhosis and hepatocellular carcinoma (HCC), the most common type of liver cancer. Although a cure for NASH is not available at this time, research is underway to identify proteins or other targets that could aid in preventing both NASH and liver cancer. In the meantime, because screening for NASH is not common and symptoms can take years to develop, it is important to learn about it and what you can do to help prevent it.

ABOUT NASH

It is normal to have some fat in your liver. When more than five percent of the liver's weight is fat, however, it is called a fatty liver and can be dangerous because the buildup of fat makes it harder for the liver to carry out its many important functions.

Some risk factors include the following:

- Being an older adult
- Being overweight or obese, especially with body fat around the abdomen
- High cholesterol, especially triglycerides
- Diabetes or being pre-diabetic
- High blood pressure
- Having a sedentary lifestyle

Though you cannot do anything about your age, you can adopt some lifestyle changes that may lower your risk. In addition, it is essential to keep regular medical appointments and communicate honestly with your doctor. Be open about symptoms you have. They may or may not be related to NASH, but providing as much detail as possible will help your doctor diagnose your condition. When symptoms of NASH occur, they may include being tired and feeling pain in the upper right side of your abdomen where your liver is located.

TESTING AND DIAGNOSING

If NASH is suspected, your doctor will consider many factors:

- Prescription and over-the-counter medi-

cines that may increase fat in your liver.

- Any alcohol use. Whether or not you drink alcohol, knowing your habits is helpful to your doctor.
- Your diet.
- Your level of physical activity.
- Your medical history and health conditions that may contribute to a fatty liver.
- Results of a physical exam, including waist circumference and body mass index (BMI).
- Blood tests to check liver enzymes, level of fibrosis (liver scarring) and blood fats, such as cholesterol.
- Test results for hepatitis C that can simultaneously affect your liver
- Specialized imaging tests that measure liver stiffness, which indicates scarring

If indicated, a specialist should perform a biopsy because that is the only way to definitively diagnose NASH.

GOING FORWARD

Whether you have NASH or are at risk for developing it, strive to do the following:

- Lose weight.
- Exercise.
- Manage existing health conditions, such as diabetes and high cholesterol.
- Avoid alcohol.
- Consult with your doctor about your use of over-the-counter medications that could affect your liver.
- Get vaccinated for hepatitis A and hepatitis B to reduce your risk of liver injury by these viruses.
- Explore clinical trials that research the relationship between lifestyle, NASH and HCC.
- Join a support group to learn from other people who are facing NASH.

Major lifestyle changes are easier to make with the support of others. Use the resources in this guide to find a local or online support group that can connect you with people whose lives are affected by NASH. ■

MULTIDISCIPLINARY TEAM



Meet Your Team

These specialists may be involved in your care.

Gastroenterologists have special training in diagnosing and treating disorders of the digestive system.

Hepatobiliary surgeons specialize in surgical procedures for the liver, bile ducts, gallbladder and pancreas.

Hepatologists (subspecialty of gastroenterology) diagnose, treat and manage diseases of the liver.

Interventional radiologists use imaging such as X-rays, CTs and MRIs to navigate small instruments, such as catheters and needles, through blood vessels and organs to treat a variety of diseases.

Liver transplant surgeons have special training in transplantation surgery.

Medical oncologists treat cancer with drug therapy and other medications.

Nutritionists/dietitians help meet nutritional challenges that arise during and after treatment.

Oncology pharmacists have special training in how to design, deliver, monitor and change drug therapy for cancer patients.

Palliative care specialists work to provide physical and emotional relief from cancer symptoms and treatment-related side effects.

Pathologists interpret the biopsy of the cells, tissues and organs removed.

Patient navigators/nurse navigators serve as guides through diagnosis, treatment and follow-up, helping identify and resolve barriers to treatment.

Pharmacists prepare and dispense prescription drugs and are a resource for side effects and drug interactions.

Radiation oncologists treat cancer using radiation therapy.

Radiologists study X-ray tests and other forms of body imaging to diagnose cancer and assess its response to treatment.

Rehabilitation specialists, including physical and occupational therapists, help improve physical strength and activities of daily living.

Surgical oncologists have special training in diagnosing and treating cancer patients that includes performing hepatobiliary operations.

Key information guides treatment

Staging liver cancer can be especially challenging because your doctor must also consider any underlying conditions you may have. This makes it important that you learn everything you can about your type of liver cancer and its stage. This information will help you to partner with your doctor as you make decisions regarding your treatment and quality of life.

Staging is a process used to describe the extent of the cancer in your body and how far it might have progressed from where it began. This will require results from physical exams, blood tests, imaging studies and biopsies. Blood tests will look for a biomarker called alpha-fetoprotein (AFP), determine whether you have hepatitis B or C, and see how well your liver is functioning. Imaging studies may include an ultrasound, computed tomography (CT), magnetic resonance imaging (MRI) and an angiogram.

Unlike with other cancers, a biopsy is not always required to establish a diagnosis of HCC. If you have an underlying liver disease such as cirrhosis and if your tumor meets all of the specific radiographic criteria to establish a diagnosis of HCC, then a biopsy is not required. There are some risks associated with liver biopsy, so a biopsy is performed only in situations in which it is deemed necessary and helpful.

UNDERSTANDING THE PATHOLOGY REPORT

The results of the physical exams, blood tests, imaging studies and biopsies are compiled with the pathology report (if one exists) and used to assign a stage to your cancer.

Staging by surgical pathology is based on careful examination of the entire tumor if resection (removal of the tumor with or without lymph nodes) is performed.

Your pathology report provides information about the unique characteristics of your cancer. It is prepared by a pathologist, who is a physician with specialized training in determining the nature of disease. The pathologist examines the tissue specimen with and without a microscope, documenting its size, describing its appearance and, sometimes, performing special testing.

Patients often do not see their pathology reports, but you can request that your doctor share yours with you.

If you decide to get a second opinion from another specialist, request that a copy of your pathology report be sent. That can be beneficial, especially if there was difficulty or controversy in interpreting the findings. Other specialists can confirm the diagnosis and stage of cancer and answer any additional questions you may have. Most doctors welcome a second opinion and will recommend another physician or hospital. Above all, the goal is for you to have the best care available.

HOW HCC IS STAGED

Because of the complexity of diagnosing liver cancer and its underlying conditions, several different staging systems have been developed. The two commonly used for HCC are the Barcelona Clinic Liver Cancer (BCLC) system and the American Joint Committee on Cancer (AJCC) staging system. To stage cancer, both use characteristics for evaluating the extent of your liver cancer, and the BCLC system also incorporates the health of your liver.

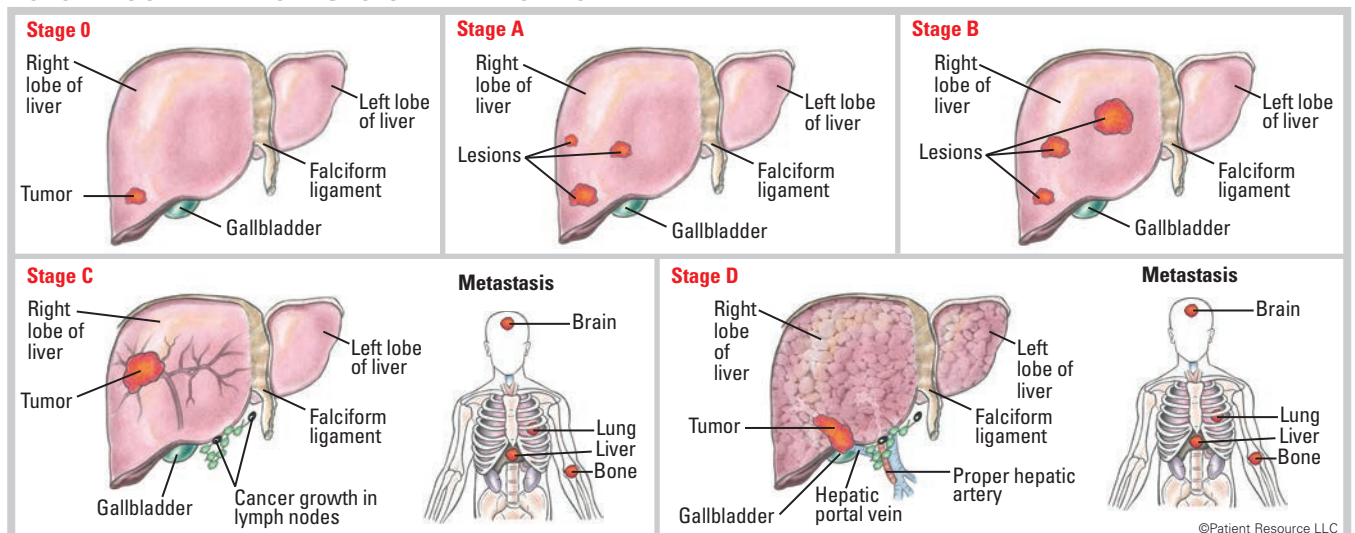
The two staging systems are explained in more detail below. Ask your doctor which system is being used and what that means for your treatment plan.

BARCELONA CLINIC LIVER CANCER SYSTEM

For staging HCC, the most commonly used system is the Barcelona Clinic Liver Cancer system (BCLC). See page 5 for BCLC staging tables and Figure 1 below for BCLC illustrations. It is based on three main factors:

1. Tumor characteristics: size, how many tumors are present and whether the tumor(s) causes symptoms.
2. The Eastern Cooperative Oncology Group (ECOG) Performance Status, which measures how the disease is affecting your ability to do daily activities. It is also a tool used to determine whether the cancer is progressing, potential treatment options and prognosis (outlook). It allows the doctor to better understand how you might tolerate treatment.

FIGURE 1
BCLC ILLUSTRATED STAGES OF LIVER CANCER



3. The Child-Pugh score, a tool for evaluating how well the liver is working. This classification system uses five factors to determine the type of treatment that may be required:

- Albumin is a protein made by the liver.
- Bilirubin is a part of bile, which is made in the liver.
- Prothrombin time is a blood test to determine how quickly the blood clots. It is sometimes reported as International Normalized Ratio (INR).
- Ascites is an accumulation of fluid in the abdomen or legs.
- Encephalopathy indicates whether liver disease is affecting brain function.

Each of these factors is scored into a point system, which tallies the number of points to assign one of three classes:

- Class A: a well-functioning liver
- Class B: liver function is significantly compromised
- Class C: severe liver damage

TABLE 1
CHILD-PUGH SCORING

Clinical Measures	1 point	2 points	3 points
Albumin (g/dL)	> (more than) 3.5	2.8-3.5	< (less than) 2.8
Bilirubin (mg/dL)	< (less than) 2.0	2.0-3.5	> (more than) 3.0
Prothrombin time (in seconds)	< (less than) 4	4-6	> (more than) 6
INR	< (less than) 1.7	1.7-2.3	> (more than) 2.3
Presence of ascites	None	Moderate	Severe
Presence of hepatic encephalopathy	None	Grades I-III (or suppressed with medication)	Grades III-IV (or refractory)
Classification	Class A	Class B	Class C
Total points	5-6 points	7-9 points	10-15 points
Indication	Indicates a well-functioning liver	Indicates liver function is significantly compromised	Indicates there is severe liver damage

TABLE 3
EASTERN COOPERATIVE ONCOLOGY GROUP (ECOG) PERFORMANCE STATUS

Grade	Description
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair

Developed by the Eastern Cooperative Oncology Group. Robert L. Comis, MD, Group Chair. Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 1982;5:649-655.

To determine the overall stage of the cancer, your doctor will combine the results from the three factors and classify the cancer into one of five stages from Stage 0 through Stage D. Following are more details about each BCLC stage.

Stage 0 (very early stage): The tumor is less than 2 cm. The ECOG Performance Status is 0, meaning you are as active as before diagnosis. The Child-Pugh score is A, meaning the liver is working normally.

Stage A (early stage): There may be one lesion that is more than 2 cm, or there are up to three lesions that measure less than 3 cm. The ECOG Performance Status is 0, meaning you are as active as before diagnosis. The Child-Pugh score is A, meaning the liver is working normally or very close to normal despite underlying damage.

Stage B (intermediate stage): There may be more than one lesion with at least one that

is more than 3 cm, or there are more than three lesions regardless of their size. The ECOG Performance Status is 0, meaning you are as active as before diagnosis. The Child-Pugh score is A, meaning the liver is working normally or very close to normal despite underlying damage.

Stage C (advanced stage): The cancer has invaded nearby blood vessels and/or has spread to lymph nodes and/or has spread to other parts of the body. The ECOG Performance Status is 1 to 2, meaning you may not be able to do heavy physical work but can do anything else, or you may be up about half the day and are unable to do any work activities. The Child-Pugh score is A, meaning the liver is working normally or very close to normal despite underlying damage.

Stage D (end-stage disease): The tumor may have grown into large blood vessels or spread to other parts of the body, and liver damage is severe. The ECOG Performance Score is 3 or 4, meaning you may be in bed or in a chair for more than half the day and you need help looking after yourself, or you are in bed or in a chair all the time and need complete care. The Child-Pugh score is B or C, meaning there is severe liver damage.

In addition, doctors may classify liver cancer based on whether it can be entirely resected (surgically removed) and may be described as the following:

- Localized resectable (confined to the liver and able to be surgically removed)
- Localized unresectable (confined to the liver but cannot be surgically removed)
- Advanced (has spread beyond the liver and likely cannot be treated with surgery)

AMERICAN JOINT COMMITTEE ON CANCER

Another way of staging liver cancer is the TNM system, developed by the American Joint Committee on Cancer (AJCC). It takes into account the tumor's characteristics, including its size, how many tumors there are, and vascular invasion, which is the presence of tumor cells within blood and/or lymph vessels. See page 6 for AJCC system staging tables and illustrations.

The TNM system created by the AJCC classifies the cancer based on four main categories: tumor (T), node (N) and metastasis (M), as well as whether the tumor is observed to have entered blood vessels.

Continued on page 6

The T category describes the size and location of the primary tumor. The N category indicates whether the lymph nodes show evidence of cancer cells. The number and location of these lymph nodes are important because they show how far the disease has spread. The M category describes metastasis (spread of cancer to another part of the body), if any. The grade describes how abnormal the cancer cells and tissue look under a microscope and how likely they are to grow and spread.

The results of the TNM analysis are then combined to determine the overall stage of the cancer for each individual. The liver cancer is then given one of the following four stages:

Stage I: A single tumor has formed but is confined to the liver and has not yet invaded any blood vessels, nearby lymph nodes or distant sites.

Stage II: A solitary tumor larger than 2 cm and cancerous cells may have grown into nearby blood vessels, or multiple tumors but none larger than 5 cm.

Stage III: Multiple tumors, at least one of which is larger than 5 cm, and/or growth into a major branch of the main blood vessels of the liver, and the cancer has not yet spread into regional lymph nodes or distant sites.

Stage IV: The tumor(s) may be any size and has spread to regional lymph nodes and/or distant parts of the body.

In some cases, your health care team may begin treatment before all of the results from the original diagnostic testing are available. Once all of the information is compiled and the stage is confirmed, your doctor may change the treatment strategy or add other forms of treatment.

If your cancer returns after treatment, you will have additional diagnostic tests that may include a biopsy, other surgical procedures, blood work and imaging studies. The new information may change your stage and your treatment plan. Cancer that is discovered early is often easier to treat, so keeping follow-up appointments to reduce the risk of a liver cancer recurrence will be very important. ■

▲ TABLE 4
AJCC STAGES OF LIVER CANCER

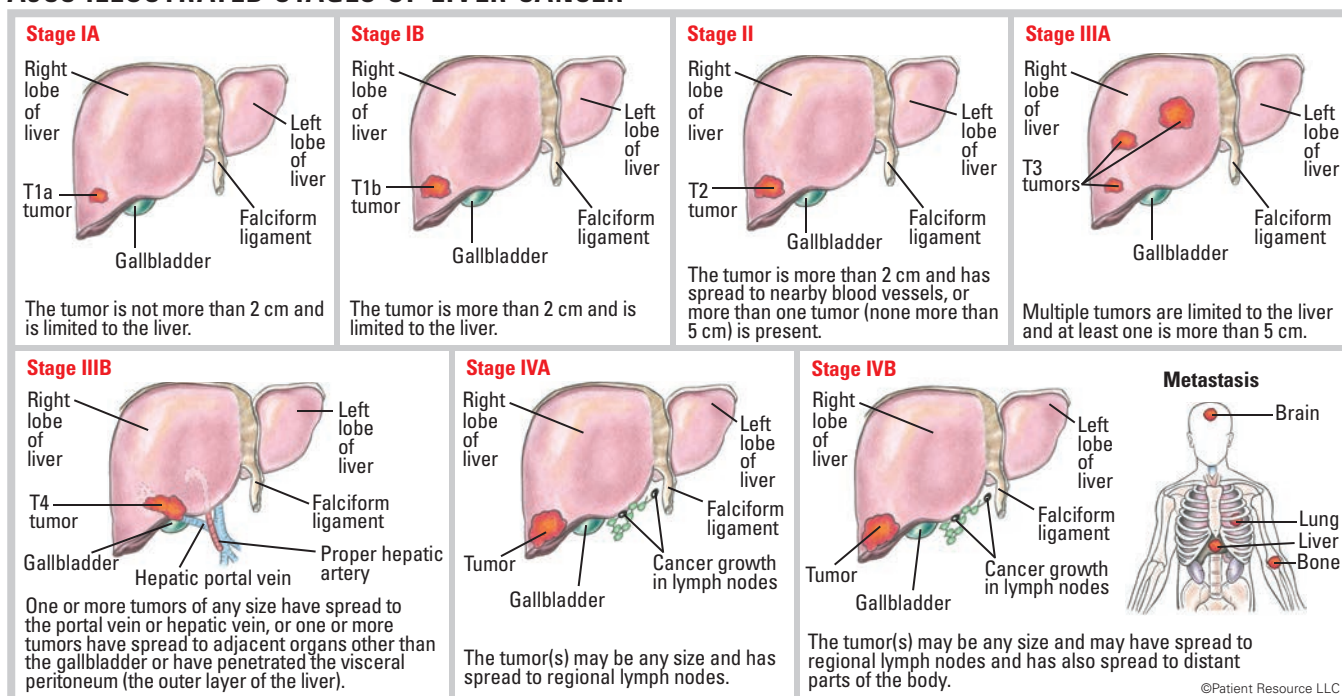
Stage	T	N	M
IA	T1a	N0	M0
IB	T1b	N0	M0
II	T2	N0	M0
IIIA	T3	N0	M0
IIIB	T4	N0	M0
IVA	Any T	N1	M0
IVB	Any T	Any N	M1

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

▲ TABLE 5
AJCC TNM SYSTEM FOR CLASSIFYING LIVER CANCER

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
T1	Solitary tumor not more than 2 cm, or more than 2 cm without vascular invasion.
T1a	Solitary tumor not more than 2 cm.
T1b	Solitary tumor more than 2 cm without vascular invasion.
T2	Solitary tumor more than 2 cm with vascular invasion, or multiple tumors, none more than 5 cm.
T3	Multiple tumors, at least one of which is more than 5 cm.
T4	Single tumor or multiple tumors of any size involving a major branch of the portal vein or hepatic vein, or tumor(s) with direct invasion of adjacent organs other than the gallbladder or with perforation of visceral peritoneum (outer layer of the liver).
Node (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Regional lymph node metastasis.
Metastasis (M)	
M0	No distant metastasis.
M1	Distant metastasis.
Grade (G)	
GX	Grade cannot be assessed.
G1	Well-differentiated.
G2	Moderately differentiated.
G3	Poorly differentiated.
G4	Undifferentiated.

▲ FIGURE 2
AJCC ILLUSTRATED STAGES OF LIVER CANCER



When facing a liver cancer diagnosis...

Lessons from Jimmy & Sharon

Helping her husband Jimmy through an aggressive case of hepatocellular carcinoma (HCC) led Sharon Dixon through uncharted territory. But one of the blessings of being his caregiver is that it positioned her to share what they learned with others who are now facing a possible liver cancer diagnosis.



Jimmy and I were friends for 30 years and married for 8. I miss him like hell every minute of every day. He once asked me, “If you’d known all of this was going to happen, would you still have married me?” I told him, “The worst day with you is still better than the best day with anyone else.”

My hope is that our story might better assist other families to avoid some of the issues we faced. Sharing what we learned helps me, and I hope it helps you, too.

► **Educate yourself.** Find out about your condition and how your lifestyle choices could contribute to a better outcome. Jimmy’s HCC diagnosis was rooted in his lifestyle. His ethnicity was also a risk factor. He was Native American and grew up in an environment where he drank and smoked heavily. As a result, he had severe liver damage that led to cirrhosis. By the time he was in his 60s and married to me, the condition had progressed to liver cancer. Understand your risk factors for developing liver cancer. Be proactive about seeing your doctor and getting tested for certain liver conditions.

► **Find a liver specialist.** HCC is so specialized that it really requires a doctor who is expertly trained to diagnose and treat it. If one is not nearby, ask for a referral from your doctor or a liver cancer advocacy group. We lived out in the country, and we didn’t have a liver specialist anywhere remotely close. It took a lot of time just to make an HCC diagnosis. Though we were fortunate to work with a great gastrointestinal doctor and interventional radiologist, we didn’t benefit from the knowledge of a liver cancer expert.

► **Take advantage of your resources.** Right off the bat, ask to speak with the social worker or patient representative at your hospital. We had challenges paying for Jimmy’s care. It’s a vicious circle. When you can’t work because of your health, you can’t have insurance. And when you don’t have insurance, it can be next to impossible to get in with a doctor, let alone get the expensive tests and care you need. Our lives changed for the better once we met a social worker who took on the many barriers to care we faced.

► **Advocate for your loved one.** Explore the treatments that are available and the side effects that accompany them so you are prepared if they happen. I didn’t know enough to really push for what we needed, and I didn’t know what to ask. Do your research, and ask lots of questions. The squeaky wheel gets the grease. As aggressive as HCC is, the speed with which you address any issue makes a difference.

► **Connect with the liver cancer community for information and support.** After I got involved with Blue Faery: The Adrienne Wilson Liver Cancer Association and other organizations to help raise awareness about liver cancer and improve treatments, Jimmy joined me. The more he participated by being on advisory boards and giving interviews that shared his experiences as an HCC patient, the more he enjoyed it. He went from “They don’t want to hear from me” to “They like me!” He even won Blue Faery’s Adrienne Wilson Spirit Award for patients.

► **Consider palliative care.** Jimmy reached the point where he wanted to stop active treatment and, instead, use the time God was giving him to make memories with me. We called in a faith-based, non-profit hospice group. Their goal was to use their palliative care services to help Jimmy have an enjoyable quality of life. What a wonderful move it was! Their nurses and chaplain were available to us in many ways, whether it was providing Jimmy medications as needed or offering emotional support.

We had one more year together, and we filled it with good memories. We bought a trailer and lived on a plot of land, worked in the garden together, even went out to dinner on New Year’s Eve and danced by ourselves in the Town Square to our song, “Tupelo Honey” by Van Morrison. Hospice had a wish fulfillment program, and Jimmy asked for something they hadn’t heard before: a wedding. We’d had a very small one, and this time he wanted to do it right. They coordinated it in our backyard, complete with decorations, flowers and a BBQ dinner.

► **Adopt the right attitude.** Jimmy was an amazing man, always positive and never angry. His priorities were God, me, family and trying to inform cancer patients and their families. Find something that gives you hope. ■

Clinical trials may be a treatment option

Most of the advances made in treating cancer today were once therapies or procedures that were developed, tested and evaluated through the clinical trials process. These highly regulated research studies rely on volunteers to help doctors search for new and better ways to prevent, diagnose, treat and cure cancer.

Researchers use different types of clinical trials to improve care for HCC and other related conditions.

Treatment trials are the most well-known type of clinical trial. They test a new medical approach that may include new drugs, drug combinations, surgeries, medical procedures or devices.

Disease prevention and patient screening trials are designed to evaluate new ways to identify or diagnose a particular condition. These trials also find ways to prevent the initial development or recurrence of a condition. These can include medicines, vaccines or lifestyle changes.

Diagnostic tools and procedures are conducted to examine new and improved methods for identifying cirrhosis or HCC and the risk factors for those conditions.

Researchers seek to learn more about the genetic disorders and disease-related mutations that cause liver diseases such as NASH, HCC and other health conditions.

Lifestyle/behavioral changes explore and measure ways to make people more comfortable as they manage a chronic condition. Some studies test the effect that lifestyle changes have on lowering the risk of NASH and HCC.

Let your doctor know if you are interested in participating in a clinical trial. Your medical team can guide you through the process, and

you can search for a trial on your own. To get started, use the list of clinical trial search sites below. Then follow these steps.

1. Gather your diagnosis and treatment information.
2. Search by your cancer type or condition. Add your age, preferred location and other details.
3. Review the list of trials and discuss those you are interested in with your doctor.
4. Contact the clinical trial team. Ask questions and take notes.
5. Undergo testing to see whether you meet the eligibility criteria.
6. Review the trial's details in the Informed Consent document, and talk it over with your loved ones.
7. Begin the clinical trial. ■

CLINICAL TRIAL RESOURCES

- ▶ **Blue Faery: The Adrienne Wilson Liver Cancer Association:** www.bluefaery.org/clinical-trials
- ▶ **Cancer Support Community:** www.cancersupportcommunity.org/find-clinical-trial, 888-793-9355
- ▶ **Center for Information & Study on Clinical Research Participation:** www.searchclinicaltrials.org
- ▶ **ClinicalTrials.gov:** www.clinicaltrials.gov ▶ **Lazarex Cancer Foundation:** www.lazarex.org, 877-866-9523
- ▶ **National Cancer Institute:** www.cancer.gov/clinicaltrials ▶ **NCI Cancer Information Service:** 800-422-6237
- ▶ **WCG CenterWatch:** www.centerwatch.com, 888-838-5578

FOR THE CAREGIVER

Approaching a role that is both physical and emotional

Being a caregiver for someone with a chronic illness such as HCC is challenging, but it can also be rewarding. To prepare yourself for what is ahead, it may help to make a plan that outlines how you can best help. Start with these suggestions and remember that your loved one's needs will change over time. Flexibility is going to be fundamental to your role.

Attend medical visits. Learn from the medical team about HCC, possible treatment options and other aspects of care. Ask for copies of test results, procedures, treatments received, etc.

Introduce yourself to the health care team. Get contact information for key team members, and find out when and how to reach out with questions and concerns. Timely topics may require a phone call or text, while others may be perfect for email or a health care portal (if available). Make sure you have signed all forms that allow you to communicate with your loved one's medical team and have set up an account on the portal.

Give and track medication. Taking medication as prescribed is crucial for treatment to work as intended. Create a chart or set reminders or alarms to make it easier to stay on schedule with medications taken at home and by appointment at the hospital or doctor's office.

Help manage side effects. Learn other side effects to watch for, when they likely will occur and what to do if they happen. Use a tracking sheet to help you remember details that you can share with your medical team. Download a tracking form at PatientResource.com/Tracker.

Surround yourself with support. Seek out a local or online cancer support group,

peer-to-peer counseling organization or a cancer caregivers' support group. It can help immensely to talk with another person who has been in your shoes.

Be empathetic. Treat your loved one the same as you did before, especially if either of you feels guilty about the diagnosis. Be proactive about connecting with other HCC survivors and caregivers to learn how they manage the feelings associated with disease stigma (see *Introduction*, page 2).

Practice self-care. To be the best source of support, you must care for yourself. Self-care will help you feel re-energized, happier and better prepared for your ongoing caregiving role. Commit to leading a healthy lifestyle. Think about the activities that make you happy. Go to the gym. Talk a walk. Do yoga. Get a massage. Read a book. Find something to laugh about every day; it is a great way to reduce stress. ■

Clinical Trials for
Adult & Pediatric
Patients with
Advanced Liver Cancer

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What is **T-cell therapy?**

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or call us at (510) 654-7045

Be an active part of your specific care plan

Progressive research in treatment is enabling some people with HCC to manage their illness as they would other chronic conditions. And for others, the advances may even mean a cure. As you learn more about your diagnosis and treatment options, you are encouraged to participate in shared decision making with your medical team. Always ask questions and share your expectations about your quality of life. Being informed will help you feel more comfortable moving forward.

To develop the most effective treatment plan, your doctor will coordinate with your medical team (see *Multidisciplinary Team*, page 3). Together, you will create a treatment plan that is based on the following:

- The results of a thorough health assessment, diagnostic tests and imaging
- How much of your liver is affected by the tumor
- The number of tumors, including their size and location
- Whether the cancer has spread outside the liver
- How well your liver is working and whether noncancerous areas remain healthy
- Any comorbidities (other serious health conditions)
- Your overall physical condition
- Your preferences about quality of life

Your prognosis (outlook) will help guide your goals of treatment. Those goals may be as follows and may change over time:

- Eliminating the HCC by curing it; also referred to as a curative treatment
- Shrinking the tumor(s) to make liver resection or transplantation possible; also referred to as downsizing the tumor
- Slowing the cancer's progression to extend life
- Using supportive (palliative) care to improve your quality of life by managing side effects, treating post-operative pain and symptoms, or helping relieve pain and discomfort without active treatment

COMMON HCC TREATMENTS

One or more of these options may be part of your treatment plan.

Surveillance (also called watchful waiting) may be recommended for tumors that appear to be growing very slowly. With close monitoring and regularly scheduled blood

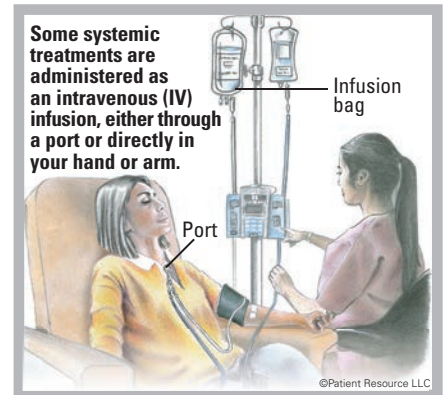
and imaging tests (every 3 months is common), this allows you to avoid potential side effects for as long as possible before treatment is necessary. Make and keep these appointments because treatment should begin if the pace of cancer progression increases.

Clinical trials are a valuable option, especially if you are diagnosed with advanced HCC. Ask your doctor whether you should consider a clinical trial immediately after diagnosis or at any other time during your treatment (see *Clinical Trials*, page 8).

Surgery is the primary curative method for treating HCC. It is often complex and requires a high degree of training and skill. It is recommended that you seek treatment at a cancer facility known for performing a high volume of liver surgical procedures, and one that has liver transplant as an option. Seek a second or third opinion before deciding on a surgeon.

Liver resection, also called a partial hepatectomy (HEH-puh-TEK-toh-mee), removes a wedge, an entire lobe or more of the liver that contains the tumor(s), along with a mar-

FIGURE 2
DRUG THERAPY

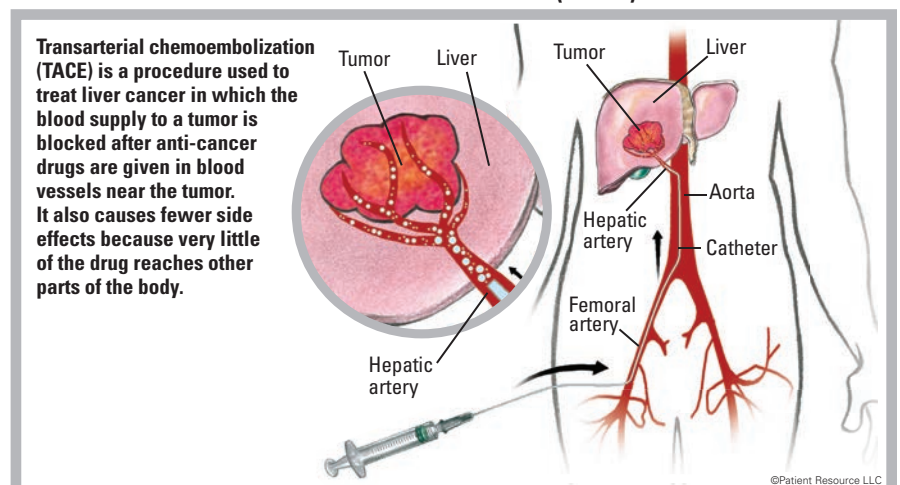


Some systemic treatments are administered as an intravenous (IV) infusion, either through a port or directly in your hand or arm.

gin of healthy tissue. The remaining healthy liver will continue to function as it regenerates (regrows), often to near normal size. This may be an option when your liver is functioning well, the tumors are small, the disease is early-stage and blood vessels are not involved. You and your liver must be healthy enough to have surgery.

- Traditional open resection is used for complex operations. The surgeon makes an incision into the abdomen. This is major surgery and requires significant recovery time.
- Minimally invasive laparoscopic surgery may be an option for resections, depending on the tumor location and surgeon experience. A few small incisions are made in the abdomen to insert a long, tube-like medical instrument (laparoscope) with a tiny video camera on the end. Magnified images from inside the body are transmit-

FIGURE 1
TRANSARTERIAL CHEMOEMBOLIZATION (TACE)



ted to a video screen in the operating room to guide the surgeon. The surgeon still typically needs to make one larger incision to remove the tumor from your abdomen. Nevertheless, this method usually results in shorter recovery time and fewer complications than traditional open resection.

Liver transplantation is a highly effective, potentially curative treatment for HCC. The entire liver is removed (hepatectomy) and replaced with a healthy liver, most often from a deceased donor. In some cases, a living donor may be used.

Only a very small percentage of people qualify for transplantation. Candidates must meet strict criteria concerning the size, stage, location and number of tumors present, and must have a qualifying “liver score” based on blood levels of creatinine, bilirubin, sodium and blood clotting factors. It is beneficial to have your evaluation in a center that performs liver transplants. If your doctors believe you may be a candidate, you can be referred for assessment to a transplant team.

If you are a candidate, you will likely undergo bridging treatment while you wait for a liver to become available. This is necessary because the wait time can be significant in some cases. Bridging therapy is designed to prevent the cancer from growing or spreading during the wait. Bridging treatments may include ablation, embolization, radiation therapy or systemic drug therapy.

Radiofrequency ablation (RFA) therapy may be a curative option for HCC when a tumor is unresectable (inoperable) or surgery is not an option for another reason. It is a minimally invasive, image-guided procedure that kills cancer cells. A needle is inserted through the skin directly into the tumor and an electrical current is run through it to subject the tumor to extreme temperatures. Other ablation therapies include the following:

- Microwave ablation (MWA) uses microwave energy.
- Cryoablation, also called cryosurgery or cryotherapy, delivers extremely cold gas through a hollow needle. This may be referred to as thermal ablation.
- Percutaneous ethanol injection (PEI), also called alcohol ablation, delivers ethanol (alcohol) directly into the tumor.

Embolization procedures are not curative but can be very effective in extending life and improving quality of life:

Transarterial chemoembolization (TACE) involves making a small incision in the groin and inserting a catheter, which is a thin, flexible tube that is guided through the body to the hepatic artery. It is a minimally invasive, image-guided procedure that treats HCC by administering chemotherapy into small hepatic arteries that are the main source of blood for most tumors developing in the liver, and then blocking them off to allow the chemotherapy to remain present in the area of the tumor for longer periods of time (see Figure 1). Very little of the chemotherapy escapes the liver, making conventional side effects from chemotherapy uncommon.

Transarterial bland embolization (TAE) is a similar procedure. When the catheter is in place, tiny particles made of gelatin beads or sponges are injected to block small arteries, cutting off the flow of blood feeding the tumor (without administration of chemotherapy). Healthy liver tissue continues to receive blood from other blood vessels.

Radioembolization, also referred to as Y90 or Yttrium 90, combines radiation therapy with embolization. Microscopic glass beads containing high-dose radiation are injected into the hepatic artery to be delivered directly to the tumor. The radiation kills many cancer cells. The goal is to slow the growth of the tumors and reduce symptoms, although radioembolization has also been used to reduce the size of tumors to permit subsequent surgical treatment.

Drug therapy may be used to manage HCC. It is systemic therapy, which means the drugs travel throughout the body (see Figure 2).

Molecularly targeted therapy is designed to slow the cancer’s progression. Drugs travel through the bloodstream looking for specific proteins and tissue environments to block cancer cell signals and thereby restrict the growth and spread of cancer. The most commonly used for HCC is an angiogenesis inhibitor. It works by blocking the growth of new blood vessels that feed the cancer cells. Blood vessels deliver nutrients the tumors need to grow and spread, so by shutting down the formation of new blood vessels, angiogenesis inhibitors in effect “starve” the tumor. Other targeted therapies treat mutations in the neurotrophic tyrosine receptor kinase (*NTRK*) (pronounced EN-track) gene, which causes cancer cells to grow.

DRUG THERAPIES FOR HCC

- ▶ cabozantinib (Cabometyx)
- ▶ entrectinib (Rozlytrek)
- ▶ larotrectinib (Vitrakvi)
- ▶ lenvatinib (Lenvima)
- ▶ pembrolizumab (Keytruda)
- ▶ ramucirumab (Cyramza)
- ▶ regorafenib (Stivarga)
- ▶ sorafenib (Nexavar)

POSSIBLE COMBINATION THERAPIES

- ▶ atezolizumab (Tecentriq) with bevacizumab (Avastin)
- ▶ ipilimumab (Yervoy) and nivolumab (Opdivo)
- ▶ tremelimumab (Imjudo) with durvalumab (Imfinzi)

As of 4/28/23

Many targeted therapies are taken orally at home. Targeted therapy may be used alone or in combination with immunotherapy.

Immunotherapy fights cancer by stimulating the body’s immune system to recognize and destroy cancer cells. Immune checkpoint inhibitors are the type of immunotherapy currently approved to be used for advanced HCC in certain instances. These drugs prevent the immune system from slowing down, allowing it to keep up its fight against the cancer. The following checkpoint receptors are targets for immunotherapy:

- PD-1 (programmed cell death protein 1) is a receptor involved with signaling T-cells to die and reducing the death of regulatory T-cells (suppressor T-cells). PD-1 can signal the immune system to slow down only if it connects with PD-L1.
- PD-L1 (programmed death-ligand 1) is a protein that, when combined with PD-1, sends a signal to reduce the production of T-cells and enable more T-cells to die. When PD-1 (the receptor) and PD-L1 (the protein) combine, the reaction signals that it is time to slow down.
- CTLA-4 (cytotoxic T-lymphocyte-associated protein 4) is another checkpoint like PD-1. CTLA-4, however, can connect with more than one protein.

This type of immunotherapy is given intravenously (IV). It may be used alone or combined with another immunotherapy or targeted therapy.

Radiation therapy uses high-energy X-rays or other types of radiation to destroy cancer cells. The goal is to shrink tumors or slow their growth. It may be used in palliative care to relieve pain and other cancer symptoms by shrinking tumors. It is sometimes referred to as stereotactic body radiotherapy (SBRT). ■

Side effect management includes your entire well-being

One of the most common fears people have about cancer treatment is the potential side effects. Although most cancer and its treatments cause side effects, you will be surrounded by a health care team who will help you manage the symptoms from the moment you receive your diagnosis. You are encouraged to talk with your medical team before treatment begins about possible side effects and what to do if they occur.

Communicating honestly about how you feel, both physically and emotionally, is an important step you can take. The sooner you share your concerns, the quicker they can be managed. It's also important to be honest with your family and caregiver about the side effects you have and their level of severity.

The advances made in treating cancer also apply to managing the side effects that accompany the diagnosis. As a result, people facing cancer have access to services that are designed to help improve their overall well-being before, during and after treatment. These are known as supportive or palliative care services.

Designed to benefit anyone with a serious or life-threatening illness, these services are available through survivorship. Palliative care is often confused with hospice care, which is reserved for end-of-life. Think of the purpose of palliative care as “quality-of-life preservation” or “quality-of-life restoration.”

This assistance will be a valuable part of your care because if liver function decreases, toxins that are normally filtered by the liver can build up. This can cause cognitive decline and other conditions that may make it difficult to think clearly. You may need help understanding the prognosis and making important care-related decisions.

Your doctor can provide you with a referral. Together with a palliative care specialist, you will develop a plan to ease symptoms. A specialist may offer the following forms of support:

- Educating you about your illness and prognosis.
- Defining your terms for quality of life.
- Coordinating care among the health professionals.
- Providing support for decision-making and stress management.
- Referring you for psychosocial support to manage depression, sleep disturbances and other mental health challenges.
- Finding financial counseling through a social worker, nurse navigator or financial counselor.
- Helping with advance care planning and assisting caregivers. Advance care planning is recommended as early as possible after diagnosis so you can make decisions before the disease progresses and interferes with normal thinking and decision-making.

The palliative care team assisting you may include doctors and nurses, mental health professionals, pain specialists, pharmacists, nutritionists and social workers. This team will work with your doctor and provide an extra layer of support to your care.

Palliative care services are often covered by individual insurance plans, Medicare and Medicaid. To learn more, talk with the hospital's social worker or financial counselor or your health insurance representative.

POTENTIALLY SEVERE SIDE EFFECTS

Serious side effects are usually uncommon, but they can occur with certain treatments. Ask your doctor whether you are at risk for side effects from the therapies in your treatment plan, how to identify the symptoms and when to seek emergency care. Report symptoms immediately so they can be treated rapidly. Some potentially severe side effects include the following:

- **Ascites** is a condition in which an abnormal amount of fluid collects in the peritoneal (abdominal) cavity. Ascites can be malignant, meaning it is caused

Caring for your emotional health

▶ **Many people rely on supportive care to manage physical side effects**, but it can also be used to help you manage the emotional challenges associated with cancer. Your family members, caregivers and others close to you can also benefit from this support.

It is common to experience a range of emotions when you receive a cancer diagnosis: sadness, anger, anxiety, depression, loneliness and even regret. It is normal to be concerned about how cancer treatments will affect your health, family and daily life.

Taking care of your emotional well-being will help you better cope with cancer-related issues, including managing physical side effects. It is important to recognize the effect that physical changes from treatment can have on your mental and emotional well-being. Supportive care services can connect you with resources to help manage these feelings.

Support is available from online and in-person support groups, counselors, psychologists, psychiatrists and other specialists. Some organizations offer one-on-one buddy programs that pair you with another person who has the same type of cancer as you. Sharing your feelings with people who can relate because they have been through something similar can be very satisfying.

Watch for scanxiety, which is a mixture of anxiety and stress that can happen when you are awaiting results from imaging scans, laboratory tests or exams you have as part of your treatment plan. That is a lot of stress to put on your mind and your body, and it may help to find ways to manage it. Set expectations with your doctor or nurse about when and how you will receive the results so you are not left waiting and wondering.

Notify your health care team if you are unable to follow treatment due to extreme emotional distress; have excessive crying or continued feelings of hopelessness or despair; are unusually angry or irritable; are withdrawing and isolating yourself from family and friends; and feeling worthless. Get immediate medical attention for thoughts of suicide or death.

➔ **MENTAL HEALTH SERVICES**

American Psychosocial Oncology Society Helpline: **866-276-7443**

by cancer cells distributed throughout the abdominal cavity, or non-malignant, meaning it is caused by something other than cancer (such as cirrhosis). It can be treated with diet, diuretics (drugs that cause the kidneys to produce more urine, ridding the body of extra fluid and salt), paracentesis (procedure to drain the fluid), chemotherapy or surgery. Your doctor will discuss the option that is best for you.

- **Fatigue** is the most common symptom reported by patients with liver disease. It is a type of tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has. Contact your doctor immediately if fatigue prevents you from carrying out your daily activities.
- **Hepatic encephalopathy** occurs when the liver is unable to filter toxins in the blood sufficiently. The buildup of these toxins affects the brain and ability of the nervous system to function. Ask your doctor about symptoms to watch for and when to go to the emergency room.
- **Infection** can occur as a result of suppression of your immune system. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4°F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching. If you cannot reach your doctor, go to the emergency room.
- **Immune-related adverse events** (irAEs) may occur with certain immunotherapy drugs if the immune system becomes overstimulated by treatment and causes inflammation in one or more organs or systems in the body. These may include the cardiovascular, endocrine, gastrointestinal, neurologic, pulmonary (lung), renal (kidneys), skin and neurologic systems. Some irAEs develop rapidly, becoming severe and even life-threatening without immediate medical attention.
- **Infusion-related reactions** most frequently occur with treatment given intravenously (IV) through a vein in your arm,

usually soon after exposure to the drug. Reactions are generally mild, such as itching, rash or fever. More serious symptoms, such as shaking, chills, low blood pressure, dizziness, breathing difficulties or irregular heartbeat, can be serious or even fatal without medical intervention.

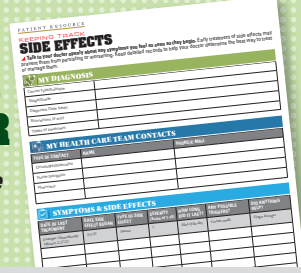
COMMON PHYSICAL SIDE EFFECTS

Managing side effects allows you to stay on treatment without interruption, makes it easier for your body to handle treatment and generally improves your well-being. It may comfort you to know that people often respond differently to the same treatments, so it is important to discuss with your doctor which side effects you may experience (see Table 1).

SIDE EFFECTS TRACKER

Use this resource to keep track of any side effects

Download at PatientResource.com/Tracker



Also, watch for possible late effects. These are side effects that develop weeks, months or even years after treatment ends. They typically are hard to predict so knowing what to do if one occurs is key.

Keeping track of your side effects helps your doctor to better manage them. The sooner side effects are addressed, the sooner you will feel better. ■

TABLE 1
SOME COMMON PHYSICAL SIDE EFFECTS*

Side Effects	Symptoms
Abdominal pain	Cramping and dull aches in the abdominal area
Ascites	Abdominal swelling from fluid accumulation in the abdomen
Bleeding problems	Hemorrhaging and bruising
Chemo brain (cognitive dysfunction)	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or less frequent bowel movements compared to your usual bowel habits
Decreased appetite	Eating less than usual, feeling full after minimal eating, not feeling hungry
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Difficulty swallowing	Also called dysphagia; may include painful swallowing
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and/or body
Hand-foot syndrome	Also known as Palmar-Plantar Erythrodysesthesia; may include pain, swelling, tightness and redness on the palms of the hands or soles of the feet; or blisters and calluses
Headache	Pain or discomfort in the head
Hypertension	Abnormally high blood pressure
Lymphedema	Swelling of the extremities
Nausea and vomiting	The feeling of needing to throw up and/or throwing up
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Pain	Musculoskeletal pain and aches that occur in the muscles, joints, bones, tendons, ligaments or nerves
Proteinuria	High levels of protein in urine
Respiratory problems	Shortness of breath (dyspnea) with or without cough, upper respiratory infections
Skin reactions	Rash, redness and irritation or dry, flaky or peeling skin that may itch
Taste changes	Foods may taste different or bland, or your ability to handle spicy, sweet or bitter foods changes
Thrombocytopenia	Low number of platelets in the blood, which can lead to bruising and bleeding
Voice changes	Also known as dysphonia, difficulty speaking or swallowing, hoarseness, raspy voice, soft voice, no voice or swelling in the throat
Weight changes	Unintentionally gaining or losing weight

*Side effects listed alphabetically. Ask your doctor what to expect with your treatment plan.

Work with specialists to develop a personal nutrition strategy

Cancer and treating it can take a toll on your body and make it difficult to consume all of the nutrients you need to fight cancer and recover. Many cancer treatments kill healthy cells as well as cancer cells. As a result, your body needs more nutrients to replenish the healthy cells that support you before, during or after treatment.

Treating cancer and its side effects can impact your ability and desire to eat, along with affect how food tastes or smells. Feeling nauseated, tired, depressed or just uncomfortable may also affect your eating habits. Your doctor may recommend nutrition therapy. This often begins with nutritional counseling, also referred to as dietary counseling, in which dietitians or professionals with special training in nutrition help you make healthy food choices and form smart eating habits. The goal of nutritional counseling is to help patients be healthy during and after treatment and to stay strong enough to prevent or manage infections and lower the risk of recurrence.

Learn about the unique nutrition challenges ahead and the options you have to get the nutrients your body needs. Meet with a registered dietitian before treatment begins. The dietitian will perform a nutritional assessment and recommend therapy to assist you through treatment to avoid weight and muscle loss, dehydration and malnutrition. A key goal will be to focus on preventing your treatment from being interrupted due to malnutrition. A dietitian will be a valuable resource for you throughout treatment and beyond. If your health care team does not have a dietitian on staff, ask for a referral.

MANAGING APPETITE LOSS

A major challenge you may face during treatment is loss of appetite. This side effect is common; however, when you can't eat or don't want to eat, you may be at risk for losing weight. Nausea may cause appetite loss. Ginger tea and chews can help reduce nausea. Also, ask your doctor for anti-nausea medication.

Because a healthy diet can help you gain strength, it helps to know what to do — and what not to do.

In general, try to consume a wide variety of healthy foods and drink plenty of liquids. Following are options to help get the most nutrition out of every bite:

- Eat protein-rich foods: chicken, fish, turkey, eggs, low-fat dairy products, nuts and soy.
- Drink high-protein or high-calorie beverages: milkshakes, smoothies and nutritional supplement beverages.
- Include colorful fruits and vegetables: apples and leafy greens. Check whether they need to be cooked before eating.
- Choose whole grains: oatmeal, whole wheat bread, brown rice and whole grain pasta.
- Switch to healthy fats: avocados, nuts, seeds and olive oil.
- Eat five to six small meals throughout the day.
- Avoid saturated and trans fats, added sugars, cakes, cookies, candies, salts, alcohol and undercooked fish or shellfish.
- Schedule your “main” meal of the day for when your appetite is best and you are able to eat the most.
- Talk with your health care team before taking vitamins or supplements as doctors prefer that you get all, or most, of your nutrients from food.
- Ask whether you would benefit from taking branched-chain amino acids.

It may be challenging to prepare meals when you have lost your appetite, feel nauseated or are tired. Conserve your energy by having foods on hand that are ready to eat or require little preparation, such as puddings, peanut butter, tuna, protein bars, trail mix, cheese and crackers, eggs and frozen meals.

UNDERSTANDING MALNUTRITION

Cancer, treatment and side effects may cause malnutrition, a condition that develops as a result of not getting enough calories and nutrients, or not being able to absorb the right amount of key nutrients, such as vitamins and minerals.

Malnutrition is surprisingly common and should be addressed to accommodate the



metabolic demand, immunosuppression and increased inflammation that treatments and underlying conditions can have on the body. It is also a concern during bridging therapy while awaiting a transplant.

Symptoms may include feeling tired and weak, and may be severe enough to prevent you from completing treatment. If you are unable to eat or do not want to eat, you may experience weight and muscle loss. If eating is difficult for these or other reasons, alternative options such as parenteral nutrition exist.

Parenteral nutrition may be an option in rare cases if your digestive tract is not working, or when a blockage is present. In this type of feeding, the nutrients you need are delivered intravenously (through a vein), usually through a port that is surgically inserted.

STAYING HYDRATED

Your body needs water to function and to prevent dehydration. Daily fluid needs vary based on health, weight, activity level and geographic area. The general recommendation is 10 cups of water per day for men and 8 cups for women. Ask your doctor about your recommended water intake.

Try to consume more fluids, including water, if you experience side effects such as diarrhea or vomiting, as they may cause you to lose additional fluid and increase your risk for dehydration. If diarrhea is severe, you may not be able to absorb plain water, and your doctor may recommend a specialized oral rehydration solution. Certain drinks can also help replenish lost electrolytes. ■

NUTRITION RESOURCES

- ▶ **American Cancer Society:**
www.cancer.org, 800-227-2345
- ▶ **CancerCare:** www.cancercare.org, 800-813-4673
- ▶ **PearlPoint Nutrition Services:**
www.pearlpoint.org, 877-467-1936

Move forward with a survivorship plan

Whether or not you are still receiving treatment, you will be checked at regularly scheduled intervals to monitor for a possible recurrence or other health care issues. These follow-up appointments are important because finding any disease recurrence early may help successful intervention.

These checkups include a review of your medical history as well as a physical exam. They may also include imaging procedures, blood tests and possibly a biopsy to gauge the cancer's response to treatment or determine whether your cancer has recurred.

Your follow-up care plan may include the following:

- Appointment schedule for ongoing monitoring
- Palliative care for physical and emotional side effects
- Medications or therapies (type, dosage, frequency and duration)
- Referral(s) for cancer rehabilitation, such as physical or occupational therapy
- Information about your risk of a recurrence, second cancers, long-term treatment-related side effects and late effects
- Recommended screening guidelines for other types of cancer.
- Meeting with a social worker to help you navigate the financial impact and your emotional well-being



Keep track of your over-the-counter medications

► Because many people with liver cancer already have some level of damage to their liver, preventing further damage is crucial. This requires ensuring your new prescriptions do not interact with your current medications and supplements.

In particular, be aware that taking acetaminophen, a common over-the-counter medication, is known to cause liver damage if taken in large quantities in people with compromised liver function. It can also interact with other medications and increase side effects. It is a common drug ingredient in many prescription and over-the-counter medications and can be found in pain relievers, fever reducers, sleep aids and cough, cold and allergy medicines.

Keep a list of active ingredient names to help you identify these drugs. Ask your doctor whether you can take medications that contain acetaminophen and, if so, how much. Follow these steps:

- Read all medicine labels, and look at the active ingredient. Ask your pharmacist how to read medication labels if you are not familiar with them.
- Find out whether your doctor recommends limiting your intake of acetaminophen.
- Check the label for acetaminophen and its shorter versions, "APAP," or "acetam."
- Take your medication as directed. Only take the recommended dose. Do not take more.
- Use the same pharmacy each time so your pharmacist can help you keep track of what you are taking.
- Do not take medication that has expired.
- Do not share medications with others.
- Always keep a list of your current medications with you.
- Take your medications with you when you travel.

These appointments also give you the opportunity to tell your health care team about new or ongoing physical symptoms that are not adequately relieved, including pain, leg swelling, abdominal distention, jaundice, weight loss or gain, bladder/bowel control, deep fatigue or insomnia, mobility issues, signs of infection, tingling or numbness, fluid buildup or changes in appetite, sense of taste, vision or hearing.

Don't forget to discuss how you feel mentally and emotionally. Specific information to discuss includes the following:

- Cognitive (thinking-related) symptoms, such as difficulties with memory, concentration, processing information, word finding or completing tasks
- Emotional issues, such as depression, anxiety, fear, anger, grief, hopelessness, feeling overwhelmed or other concerns
- Any visits to the emergency room, urgent care or other doctors
- New medications, over-the-counter remedies, vitamins, supplements or herbs, including homeopathic or naturopathic therapies


WHAT SURVIVORSHIP MEANS

Once therapy is finished or as you continue with maintenance therapy, you will work closely with your doctor to develop a survivorship plan.

This plan is designed to keep track of all pertinent information about your care and may include your medical history and ongoing medications; a list of health care team members with contact information; your specific diagnosis, including type, subtype, stage, any known biomarkers and date of diagnosis; pathology and consultation notes; and a treatment summary. It may also include the tests you may need after treatment.

Ask your doctor for a plan, or start one on your own. Download and print a sample Survivorship Care Plan at PatientResource.com/SurvivorshipPlan. Then, request copies of all your test and biopsy results, surgeries, pathology reports and consultation notes from your doctor's office to fill it in.

It is also recommended that you keep a copy of pertinent information with you to share with health care providers you encounter who are unfamiliar with your situation. Download and print this Wallet Card: PatientResource.com/Wallet_Card. ■

 (cut along dotted line)

Emergency Medical Information

Attention health care providers: please read before treating

My Name: _____

Cancer DX & Stage: _____

Oncologist's Name: _____

Phone: _____ Emergency Contact/Phone: _____

Current drug therapies that may cause a severe side effect:

Drug Allergies: _____

Support and financial resources available for you

CANCER EDUCATION

American Cancer Society	www.cancer.org, 800-227-2345
American Society of Clinical Oncology	www.cancer.net, 888-651-3038
CANCER101	www.cancer101.org, 646-638-2202
CancerCare	www.cancercares.org, 800-813-4673
Cancer Support Community	www.cancersupportcommunity.org, 888-793-9355
Centers for Disease Control and Prevention (CDC)	www.cdc.gov, 800-232-4636
Get Palliative Care	www.getpalliativecare.org
National Cancer Institute	www.cancer.gov, 800-422-6237
National Comprehensive Cancer Network (NCCN)	www.nccn.org, 212-690-0300
Patient Resource	www.patientresource.com, 800-497-7530

CAREGIVERS & SUPPORT

BeholdBeGold	www.beholdbegold.org
Cactus Cancer Society	www.cactuscancer.org
CanCare	www.cancares.org, 713-461-0028
CANCER101	www.cancer101.org, 646-638-2202
Cancer and Careers	www.cancerandcareers.org, 646-929-8032
CancerCare	www.cancercares.org, 800-813-4673
Cancer Connection	www.cancer-connection.org, 413-586-1642
Cancer Hope Network	www.cancerhopenetwork.org, 877-467-3638
Cancer Really Sucks!	www.cancerrealsucks.org
Cancer Support Community	www.cancersupportcommunity.org, 888-793-9355
Cancer Support Services	www.cancersupportservices.org, 877-593-4212
Cancer Survivors Network	csn.cancer.org, 800-227-2345
Caregiver Action Network	www.caregiveraction.org, 855-227-3640
CaringBridge	www.caringbridge.org, 651-789-2300
Center to Advance Palliative Care	www.capc.org, 347-835-0658
Chemo Angels	www.chemoangels.com
Cleaning for a Reason	www.cleaningforareason.org
Connect Thru Cancer	www.connectthrucancer.org, 610-436-5555
Cooking with Cancer	www.cookingwithcancer.org, 205-978-3570
Family Caregiver Alliance	www.caregiver.org, 800-445-8106
Friend for Life Cancer Support Network	www.friend4life.org, 866-374-3634
The Gathering Place	www.touchedbycancer.org, 216-595-9546
Guide Posts of Strength, Inc.	www.cancergps.org, 336-883-4483
Imerman Angels	www.imermanangels.org, 866-463-7626
Living Hope Cancer Foundation	www.getupandlive.org
Lotsa Helping Hands	www.lotsahelpinghands.com
MyLifeLine	www.mylifeline.org, 888-793-9355
National LGBT Cancer Project	www.lgbtcancer.org, 917-301-1913
Patient Empowerment Network	www.powerfulpatients.org, 833-213-6657
SHARE Caregiver Circle	www.sharecancersupport.org/caregivers-support, 844-275-7427
Stronghold Ministry	www.mystronghold.org, 877-230-7674
Triage Cancer	www.triagecancer.org, 424-258-4628
Well Spouse Association	www.wellspouse.org, 732-577-8899
weSPARK Cancer Support Center	www.wespark.org, 818-906-3022
Wigs & Wishes	www.wigsandwishes.org, 856-582-6600

INSURANCE PREMIUM EXPENSES

CancerCare Co-Payment Assistance Foundation	www.cancercaresupport.org, 866-552-6729
HealthWell Foundation (diagnosis-specific)	www.healthwellfoundation.org, 800-675-8416
Patient Advocate Foundation Co-Pay Relief	www.copays.org, 866-512-3861

LIVER CANCER

American Liver Foundation	www.liverfoundation.org
Blue Faery: The Adrienne Wilson Liver Cancer Association	www.bluefaery.org
Global Liver Institute	www.globalliver.org
Say YES to Hope	www.beatlivertumors.org, Survivor Hotline 877-937-7478

PRESCRIPTION EXPENSES

America's Pharmacy	www.americaspharmacy.com, 888-495-3181
CancerCare Co-Payment Assistance Foundation	www.cancercaresupport.org, 866-552-6729
Cancer Financial Assistance Coalition	www.cancerfac.org
Good Days	www.mygooddays.org, 972-608-7141
HealthWell Foundation	www.healthwellfoundation.org, 800-675-8416
Medicine Assistance Tool	www.medicinesupporttool.org, 571-350-8643

NeedyMeds	www.needymeds.org, 800-503-6897
Patient Access Network Foundation	www.panfoundation.org, 866-316-7263
Patient Advocate Foundation Co-Pay Relief	www.copays.org, 866-512-3861
RxAssist	www.rxassist.org
RxHope	www.rxhope.org
SingleCare	www.singlecare.com, 844-234-3057
Together Rx Access	www.togetherrxaccess.com, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

AstraZeneca Access 360	myaccess360.com/patient, 844-275-2360
AstraZeneca Patient Savings Programs for Specialty Products	astrazenecaspecialtysavings.com, 844-275-2360
AstraZeneca Prescription Savings Program (AZ&ME)	azandmeapp.com, 800-292-6363
Avastin Access Solutions	www.avastin.com/patient/financial-resources.html, 877-436-3683
Bristol-Myers Squibb Access Support	bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation	bmspaf.org, 800-736-0003
Cabometyx EASE	www.cabometyx.com/cost-financial-support, 844-901-3273
Cyramza Financial Support	lillyoncologysupport.com/cyramza-financial-support, 866-472-8663
Eisai Patient Support	www.eisair reimbursement.com
Exelixis Patient Access	www.exelixis.com/access
Genentech Access Solutions	genentech-access.com/patient, 877-436-3683
Genentech Oncology Co-pay Assistance	copayassistancenow.com/patients, 855-692-6729
Genentech Patient Foundation	gene.com/patients/patient-foundation, 888-941-3331
Imfinzi Access 360	myaccess360.com/patient/imfinzi-durvalumab, 844-275-2360
Imjudo Access 360	myaccess360.com/patient/imfinzi-durvalumab, 844-275-2360
Keytruda KEY+YOU	www.keyplusyou.com, 855-398-7832, press 2
Keytruda Merck Access Program	merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Lenvima Eisai Reimbursement Resources	eisair reimbursement.com/patient/lenvima, 866-613-4724
Lilly Cares Foundation Patient Assistance Program	www.lillycares.com, 800-545-6962
Lilly Oncology Support Center	www.lillyoncologysupport.com, 866-472-8663
Merck Access Program	www.merckaccessprogram.com/hcc/
Merck Patient Assistance Program	merckhelps.com, 800-727-5400
Opdivo BMS Access Support	bmsaccesssupport.bmscustomerconnect.com/patient/financial-support, 800-861-0048
Rozlytrek Access Solutions	genentech-access.com/patient/brands/rozlytrek, 877-436-3683
Stivarga \$0 Co-Pay Program	www.zerocopaysupport.com/stivarga, 866-581-4992
Stivarga Access Services by Bayer	www.stivarga-us.com/access-services-by-bayer, 800-288-8374
Tecentriq Access Solutions	genentech-access.com/patient/brands/tecentriq, 877-436-3683
Vitrakvi Access Services by Bayer	www.vitrakvi-us.com/patient-assistance-program, 800-288-8374
Yervoy BMS Access Support	bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048

TRANSPORTATION & TRAVEL RESOURCES

The Air Care Alliance	www.aircarealliance.org, 215-395-1645
Air Charity Network	www.aircharitynetwork.org, 877-621-7177
Allyson Whitney Foundation	www.allysonwhitney.org, 845-707-4681
American Cancer Society (Hope Lodge)	www.cancer.org/hopelodge, 800-227-2345
American Cancer Society (Road to Recovery)	www.cancer.org/roadtorecovery, 800-227-2345
American Childhood Cancer Organization	www.acco.org, 855-858-2226
Angel Flight Central	www.angelflightcentral.org, 866-569-9464
CancerCare	www.cancercares.org, 800-813-4673
Chai Lifeline	www.chailifeline.org, 877-242-4543
Compass to Care	www.compassforcare.org, 773-657-3269
Corporate Angel Network	www.corpangelnetwork.org, 914-328-1313
Family Reach Foundation	www.familyreach.org, 973-394-1411
Fisher House Foundation	www.fisherhouse.org, 888-294-8560
Healthcare Hospitality Network, Inc.	www.hhnetwork.org, 800-542-9730
Hospitality Homes	www.hosp.org, 888-595-4678
Joe's House	www.joeshouse.org
Lifeline Pilots	www.lifelinepilots.org, 800-822-7972
Mercy Medical Angels	www.mercymedical.org, 757-318-9174
National Cancer Assistance Foundation	www.natcaf.org, 866-413-5789
Operation Liftoff	www.operationliftoff.com
Patient Access Network Foundation	www.panfoundation.org, 800-394-0161
Patient AirLift Services	www.palservices.org, 888-818-1231
Stupid Cancer	www.stupidcancer.org, 212-619-1040
Veterans Airlift Command	www.veteransairlift.org, 952-582-2911

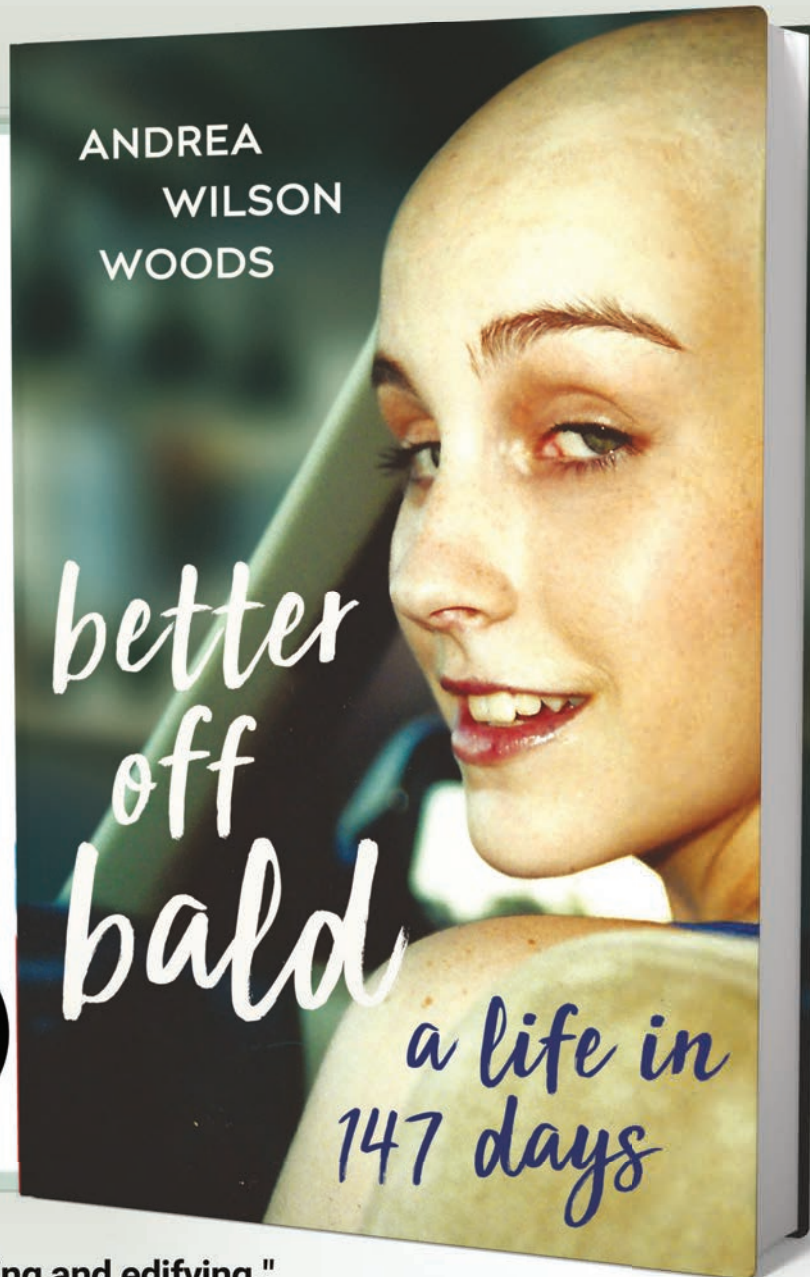
➔ For more resources, go to PatientResource.com

better off bald

a life in 147 days



"*Better Off Bald* is the beautiful and painful true story of how the author lovingly shepherds her sister Adrienne through diagnosis and treatment of advanced liver cancer, striking at far too young an age. **I wish for every doctor and medical trainee to read this book.** Andrea Wilson Woods' words bring to vivid life both the devastation—as well as moments of joy—that flooded these sisters' lives as they navigated the medical system, faced cancer, experienced suffering and courage, and held fast to each other." — Dr. Jesse Civan, transplant hepatologist



"Devastating and heartbreaking, inspiring and edifying."

~ Pacific Book Review

"The author captures the reader's heart and attention with clarity and grit."

~ Literary Titan

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