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LIVER CANCER

A Treatment Guide for Patients and their Families



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



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LIVER CANCER



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Understanding this unique diagnosis helps guide your path ahead

Your liver is essential. You cannot survive without it. It is a vital organ that performs more than 500 functions in your body, including cleaning your blood by filtering out toxins and waste, secreting bile to the intestines to aid with digestion and making clotting factors to help stop bleeding. Because cancer can impair the liver's many functions, it is crucial to learn as much as you can about your diagnosis so you can make informed decisions.

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. There are two main types of primary liver cancer: hepatocellular carcinoma (HCC) and cholangiocarcinoma. When other types of cancer metastasize, they can spread to the liver; however, that is considered secondary liver cancer.

The information in this guide focuses on HCC and is designed to help you learn more about an HCC diagnosis.

ABOUT THE LIVER

The liver has two lobes and is located on the upper right side of the abdomen above the stomach, protected by the ribs (see Figure 1). It is the largest organ in the body and the only one with the ability to regenerate, or grow back, when part of it is removed, as long as the remaining part of the liver is healthy. A liver afflicted with a chronic disease such as cirrhosis cannot regrow.

HOW HCC DEVELOPS

Healthy cells typically divide in an orderly fashion. When worn out or damaged, they die and are replaced by new cells. But cancer develops when genes begin to change, or mutate, within otherwise normal cells. Cancer cells behave abnormally, dividing rapidly, growing out of control and pushing out healthy cells. Unchecked, these cancer cells eventually form a tumor.

HCC begins in the hepatocellular cells of the liver tissue, generally in the presence of underlying chronic liver disease. Two conditions must be addressed: the cancer and the underlying liver disease. That is why liver cancer is sometimes referred to as a disease within a disease and why it is challenging to diagnose and treat.

Cirrhosis, which is scarring of the liver, is the most common underlying condition of HCC. This long-lasting, progressive disease causes inflammation and irreversible damage over time as scar tissue slowly replaces healthy liver cells and the organ gradually loses function. Another condition is nonalcoholic fatty

liver disease (NAFLD) and its most severe form, nonalcoholic steatohepatitis (NASH) (see *Fatty liver disease can lead to HCC*, page 3). Both have been linked to obesity. Viral hepatitis B and C (HBV and HCV), which are carried and spread through contact with blood and other bodily fluids, are other potential underlying conditions. Though most patients with HCC have an underlying liver disease, some patients will have a normal liver.

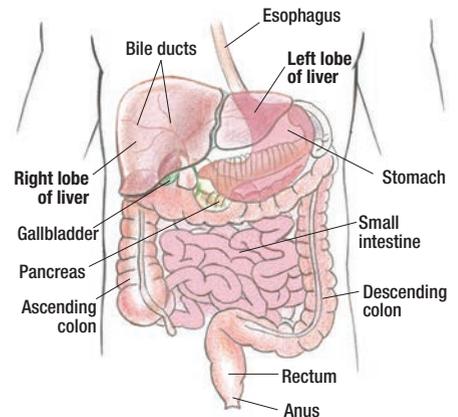
Although it is common not to feel any symptoms, many may occur, including the following:

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

Advanced cancer may result in swelling in the legs or abdomen (ascites); unexplained fevers and jaundice, which can cause yellow skin and yellowing in the whites of the eyes; dark urine and light-colored stools.

Multiple tumors may develop simultaneously. When cancer becomes advanced and spreads beyond the liver, the most common sites are the lung, abdominal lymph nodes and bone.

FIGURE 1
ANATOMY OF THE ABDOMEN



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MOVING FORWARD

Your treatment plan will have many moving parts. Your team will look at any underlying liver disease, other serious health conditions and the malignant tumors caused by HCC. Ideally, you would have a multidisciplinary team of specialists from a cancer center or hospital with significant experience treating liver cancer. Experts are required to accurately diagnose and stage the cancer, plan effective treatment and coordinate supportive care to help manage side effects (see *Supportive Care*, page 14).

Depending on your diagnosis, you may consider participating in a clinical trial. As you and your doctors discuss treatment options, ask about clinical trials taking place in the U.S. and in other parts of the world. In some situations, a clinical trial may offer the best chance for a positive outcome. Every trial has certain eligibility requirements and some may be closed. Check back often for new trials (see *Clinical Trials*, page 7).

DEMOGRAPHICS

► In the U.S., HCC is more commonly associated with the following risk factors. Although many are out of your control, you can make lifestyle choices that may reduce your chance of an underlying condition giving rise to liver cancer. In some cases, no risk factors are found, and it is not known what causes the liver to become compromised and vulnerable to HCC.

RISK FACTORS

Age: Older than 60

Ethnicity (U.S.): Higher incidence rates are found in Asians and Pacific Islanders, African Americans, Hispanics and American Indians/Alaska Natives

Lifestyle: Cirrhosis, NASH, obesity and certain environmental factors

Positive for hepatitis B or hepatitis C: Ask your doctor about hepatitis B vaccinations and blood tests for the presence of hepatitis C

Seeking a second opinion is encouraged, especially if your physician does not have extensive experience treating liver cancer. Consulting with another physician does not mean you mistrust your doctor. Rather, it means you are taking control of your health. Another opinion will confirm your current treatment plan or add new recommendations to consider. Never feel guilty for gathering as much information as you can. You deserve to know all your options so you can make more confident decisions.

PUSHING PAST THE STIGMA

No one deserves cancer, regardless of lifestyle choices. Yet many medical conditions, including HCC, are often accompanied by “disease stigma.” Disease stigma occurs when people make negative assumptions about or assign blame to individuals with certain diagnoses.

Because HCC is often related to underlying conditions that are directly related to lifestyle choices, some people diagnosed with it feel embarrassed and ashamed. These intense feel-



“ / SURVIVOR VOICE / Helen R.

“When I was first diagnosed with Stage IV hepatocellular carcinoma, a nurse practitioner who worked in my liver surgeon’s office said to me, ‘We have someone working here who had the same thing you have, and she’s been in remission for five years.’ That was all I needed to hear, that one person had survived. I had hope.”

ings can cause them to withdraw. They may avoid friends and family, which can affect their emotional well-being. They may even avoid medical appointments, which, in turn, can affect their outcome. Loved ones and caregivers can also feel this burden.

So, how do you get past feeling guilt or embarrassment that you or your loved one is responsible for this diagnosis? Surround yourself with support, and remember that you do not have to face HCC alone. A variety of resources at most cancer centers and hospitals and through advocacy groups are available to offer support. Talking with others whose lives

are affected by HCC will be invaluable. Supportive care specialists address the emotional, practical and spiritual issues that may affect you, your caregiver and/or your loved ones. Access these services as soon as possible. ■

[KEY TAKEAWAYS]

- ▶ **Your body cannot survive without your liver, a vital organ that performs more than 500 important functions.**
- ▶ **If you have NASH, changing some lifestyle habits may help you manage your condition.**

▲ NASH

Fatty liver disease can lead to HCC

➔ **Nonalcoholic steatohepatitis (NASH)** is a form of fatty liver disease characterized by inflammation, swelling and liver damage. Long-term complications can include cirrhosis and, in turn, hepatocellular carcinoma (HCC), a type of liver cancer. Because screening for NASH is not commonplace and it can take years for symptoms to occur, it is important to know if you are at risk and how to identify the warning signs.

Understanding NASH

Fatty liver disease that is not related to significant alcohol consumption is called nonalcoholic fatty liver disease (NAFLD). NASH is the most severe form of NAFLD.

Some fat in the liver is normal. But, if more than five percent of the liver’s weight is fat, it is considered to be a fatty liver. The buildup of fat makes it harder for the liver to function.

Are you at risk?

It is important to be in tune with your body, keep regular medical appointments and communicate openly and honestly with your doctor — especially if any of these common risk factors apply to you:

- 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

When symptoms do 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:

- Medicines you take that may increase fat in your liver.

- Any alcohol use, if applicable. You may or may not drink alcohol, but knowing your habits is helpful to your doctor.
- Your diet and level of physical activity.
- Your medical history and health conditions that may contribute to a fatty liver.
- Results of a physical exam, including body mass index (BMI) and waist circumference.
- Blood tests to check liver enzymes, level of fibrosis (liver scarring) and blood fats, such as cholesterol. Tests to rule out hepatitis C and other less common causes of fat in the liver may be run.
- Specialized imaging tests that measure liver stiffness, which indicates scarring.

If the results of these diagnostic tests lead your doctor to believe you may have NASH, a specialist should perform a biopsy. That is the only way to definitively diagnose NASH.

Prevention and management

If you are diagnosed with NASH or your doctor is concerned that you may develop it, consider making the following permanent lifestyle changes to reduce the fat, inflammation and fibrosis in your liver:

- 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 failure.
- 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.

Staging lays the groundwork for treatment planning

Once your diagnosis is made, a process called staging is used to describe the extent of cancer within your body and how far it may have progressed from where it began. Staging helps your doctor select the most effective treatment option for you and assists with determining a prognosis (outlook). To assign a stage, your doctor will evaluate your pathology report, including the results of your tissue biopsy, imaging studies, diagnostic tests and physical exams (see *Pathology Report*, page 7).

How your liver cancer is staged can be complex and may be confusing, so it is important to be educated about the disease. Ask your doctor or nurse to explain anything that is unclear to you. This knowledge will allow you to take an active role in your treatment plan, and you will feel better prepared to make decisions as you and your doctor plan and manage your overall care.

UNDERSTANDING THE STAGING SYSTEMS

The two staging systems most commonly used for HCC are the Barcelona Clinic Liver Cancer (BCLC) system and the American Joint Committee on Cancer (AJCC) staging system. Some doctors may use a different system so it is important to make sure you understand the system your doctor uses.

The most commonly used staging system is the BCLC. It is based on three main factors:

- 1. Tumor characteristics**, including the size of the tumor(s), how many tumors are present and whether the tumor(s) causes symptoms.
- 2. The Eastern Cooperative Oncology Group (ECOG) Performance Status** 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.
- 3. The Child-Pugh score** is used to evaluate liver function. This classification system uses five factors to determine the type of treatment that may be required. The measures are combined into a scoring system that provides doctors with information on how well the liver is working:
 - Albumin is a protein made by the liver.
 - Bilirubin is a part of bile, which is made in the liver.
 - Prothrombin time is how quickly the blood clots. It is sometimes reported as International Normalized Ratio (INR).
 - Ascites is an accumulation of fluid in the abdomen.

- 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

Your doctor will determine the overall stage of the cancer by combining the results from the three factors, which include the tumor characteristics, the ECOG Performance Status and the Child-Pugh score.

The BCLC system may be classified into one of five stages from Stage 0 through Stage D. See page 5 for BCLC staging tables and illustrations. 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 to C, meaning the liver may be working normally, may have mild to moderate damage or may have severe 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 to C, meaning the liver may be working normally, may have mild to moderate damage or may have severe 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 to C, meaning the liver may be working normally, may have mild to moderate damage or may have severe 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 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)

Another staging system that may be used is the TNM system developed by the American Joint Committee on Cancer (AJCC).

The TNM staging system classifies the cancer by tumor (T), node (N) and metastasis (M). 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.

A combination of T, N and M is used to assign an overall stage to the cancer. Liver cancers may be Stage I through Stage IV. Stages I, II and III are generally confined to the local area where the cancer is found. Stage IV has likely spread to lymph nodes and other systems in the body. Stage IV is further divided into Stages IVA and IVB. See page 6 for AJCC system staging content and illustrations.

Understanding the system your doctor uses

STAGING SYSTEM: BARCELONA CLINIC LIVER CANCER (BCLC)

Following is the Barcelona Clinic Liver Cancer (BCLC) staging system along with staging illustrations. Factors taken into consideration include the Eastern Cooperative Oncology Group (ECOG) Performance Status, which measures how the disease is affecting your ability to conduct daily activities, and the Child-Pugh scoring system, the most commonly used staging system for hepatocellular carcinoma, which is used to evaluate liver function (see page 4).

Using BCLC, Stage 0 indicates the smallest amount of tumor cells present, and Stage D represents the largest amount. Once the stage is determined, it is subcategorized to signify the health of the liver: “A” indicates a well-functioning liver, “B” represents liver function that is significantly compromised, and “C” indicates severe liver damage. *(continued on page 6)*

ADDITIONAL STAGING SYSTEMS

Along with BCLC and AJCC (see page 6), other staging systems that may be used include the Cancer of the Liver Italian Program (CLIP) system and the Okuda system. If a doctor uses one of these systems, be sure to ask questions about your stage of cancer.

Also, ask your doctor to explain how the staging system used will influence your treatment plan. Understanding as much as you can about your exact diagnosis will make you feel better prepared to make informed decisions about your care.

THE BARCELONA CLINIC LIVER CANCER (BCLC) SYSTEM

BCLC Stage	Details
0 (very early stage)	<ul style="list-style-type: none"> Tumor less than 2 cm ECOG Performance Status 0 Child-Pugh A
A (early stage)	<ul style="list-style-type: none"> Solitary lesion more than 2 cm or early multifocal disease characterized by up to 3 lesions measuring less than 3 cm ECOG Performance Status 0 Child-Pugh A to C
B (intermediate stage)	<ul style="list-style-type: none"> Multifocal disease: More than one lesion with at least one over 3 cm, or more than 3 lesions regardless of their size ECOG Performance Status 0 Child-Pugh A to C
C (advanced stage)	<ul style="list-style-type: none"> Vascular invasion and/or nodal disease and/or metastatic disease ECOG Performance Status 1-2 Child-Pugh A to C
D (end-stage disease)	<ul style="list-style-type: none"> Tumor may have grown into large blood vessels or spread to other parts of the body. Severe liver damage. ECOG Performance Status 3 or 4 Child-Pugh C

CHILD-PUGH SCORING

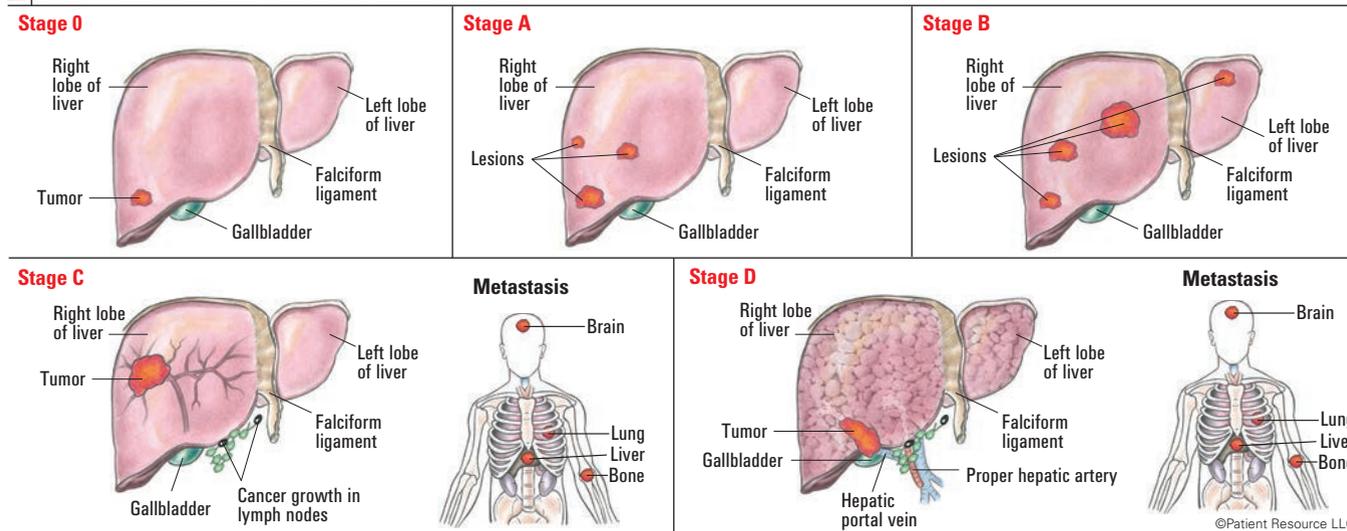
Clinical Measures	1 point	2 points	3 points
Albumin (g/dL)	> (more than) 3.5	2.8-3.5	< (less than) 2.8
Bilirubin (mg/dL)	< (less than) 2.0	2.0-3.5	> (more than) 3.0
Prothrombin time (in seconds)	< (less than) 4	4-6	> (more than) 6
INR	< (less than) 1.7	1.7-2.3	> (more than) 2.3
Presence of ascites	None	Moderate	Severe
Presence of hepatic encephalopathy	None	Grades I-II (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

EASTERN COOPERATIVE ONCOLOGY GROUP (ECOG) PERFORMANCE STATUS

Grade	ECOG
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.

BCLC — ILLUSTRATED STAGES OF LIVER CANCER



STAGING SYSTEM: AMERICAN JOINT COMMITTEE ON CANCER (AJCC)

The American Joint Committee on Cancer’s (AJCC) TNM staging system may be used to classify and stage liver cancer. Although cancers with similar stages tend to have a similar outlook and are often treated in much the same way, your doctor will also consider the results of your physical exam, biopsy and imaging tests.

The AJCC system classifies the cancer by tumor (T), node (N) and metastasis (M), as well as histologic grade. 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.

In general, using the TNM system, liver cancer may be classified into one of these four stages:

Stage I: A 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: There may be more than one tumor, and cancerous cells may have grown into nearby blood vessels.

Stage III: There is a large tumor or more than one tumor, but the cancer has not yet spread in lymphatic channels or bloodstream to 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.

Despite treatment, it is possible or even likely for HCC to return. If that happens, your treatment team will use additional diagnostic tests, such as a biopsy or surgical procedure, to verify your cancer stage. Final staging may occur after treatment has begun. Once your stage is confirmed, your treat-

ment team will be able to determine whether another form of treatment is necessary. ■

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.

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.

AJCC — ILLUSTRATED STAGES OF LIVER CANCER

Stage IA

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, T1a tumor

The tumor is not more than 2 cm and is limited to the liver.

Stage IB

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, T1b tumor

The tumor is more than 2 cm and is limited to the liver.

Stage II

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, T2 tumor

The tumor is more than 2 cm and has spread to nearby blood vessels, or more than one tumor (none more than 5 cm) is present.

Stage IIIA

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, T3 tumors

Multiple tumors are limited to the liver and at least one is more than 5 cm.

Stage IIIB

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, Hepatic portal vein, Proper hepatic artery, T4 tumor

One or more tumors of any size have spread to the portal vein or hepatic vein, or one or more tumors have spread to adjacent organs other than the gallbladder or have penetrated the visceral peritoneum (the outer layer of the liver).

Stage IVA

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, Tumor, Cancer growth in lymph nodes

The tumor(s) may be any size and has spread to regional lymph nodes.

Stage IVB

Right lobe of liver, Left lobe of liver, Falciform ligament, Gallbladder, Tumor, Cancer growth in lymph nodes

The tumor(s) may be any size and may have spread to regional lymph nodes and have also spread to distant parts of the body.

Metastasis

Brain, Lung, Liver, Bone

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Key document reveals the specifics of your diagnosis

D *Diagnosing liver cancer* and accurately identifying all the characteristics of the tumor(s) are very important for determining prognosis and possible treatment options. The accuracy of testing and interpretation is essential because treatment is planned according to the final results.

Your liver cancer diagnosis is most often based on the careful examination of a tissue biopsy from a suspected tumor or of the entire tumor after definitive surgery (removal of the tumor with or without lymph nodes).

A pathologist who has special training in determining the nature and cause of disease will examine the tissue removed during a biopsy. Thin sections of tissue will be placed on slides, stained with dyes and examined under a microscope.

The pathologist then prepares a pathology report after examining the specimen with and without a microscope, documenting its size, describing its appearance and sometimes performing special testing. The final diagnosis is based on all the findings of the examination and is included in your pathology report.

Often, patients do not see their pathology reports, but you can request that your doctor share yours with you. Pathology reports may

look different at different cancer centers and hospitals, but most of them include the same information. The details may seem overwhelming, and you will likely encounter unfamiliar terms. Ask your doctor to explain the information in it. Once you learn more, you will be more informed about your diagnosis and better able to discuss potential treatment options with your doctor.

A pathology report may include some of the following descriptions.

- Size and location of the tumor(s)
- Type of liver cancer (hepatocellular carcinoma, cholangiocarcinoma or angiosarcoma)
- Lymph node status
- Microscopic description, which compares it with normal cells
- Tumor margins (the healthy area around the tumor)
- Results of molecular diagnostic and cytogenetic studies, which look for biomarkers

and genetic or molecular abnormalities in specimens

You may feel overwhelmed with the new information surrounding your diagnosis. To help ensure you understand the diagnosis and suggested treatment plan, consider seeking a second opinion from another doctor and pathologist who have experience with HCC. Other specialists can confirm your diagnosis and might suggest changes or alternatives to the proposed treatment plan. They can also answer any additional questions you may have.

Seeking a second opinion does not mean you question your doctor. Doctors in each oncology specialty bring different training and perspectives to cancer treatment planning. Another doctor's opinion may change the diagnosis or reveal a treatment your first doctor was not aware of. A second opinion is also a way to ensure your pathology diagnosis and staging are accurate, and to make you aware of potential clinical trials. It is common for patients to request a second opinion, and you will not harm your relationship with your doctor by requesting a second opinion. ■

How to search for a clinical trial

L *Looking for a clinical trial* is one way to be an active participant in your own care. First, let your medical team know you are open to participating. While they use their resources to find available trials, you can search online websites on your own. Get started with the list of clinical trial websites on page 17. Your doctor may recommend additional resources.

Before you begin, have your diagnosis, pathology report and details of previous cancer treatments and underlying conditions on hand.

To help find a clinical trial online that may apply to you, you'll have to provide key information, such as your diagnosis. To further customize your search, enter details, such as age and underlying conditions.

You will be asked about your preferred location. If you prefer a clinical trial close to home, enter your home address. Expand the miles surrounding your home if you are willing and able to travel for treatment.

You can refine your search even more by adding a particular treatment type, such as "immunotherapy" or a particular genetic mutation, such as "NTRK" (pronounced EN-track). You

can also add a National Clinical Trial identifier, which is a unique eight-digit code preceded by "NCT" that is assigned to each trial.

READING YOUR SEARCH RESULTS

Next, you will see a list of trials that match your criteria. Details include recruitment status, which indicates whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. Be aware that the status will change, so check often for updates.

The Summary of Study explains the purpose of the clinical trial and the treatment being studied. This section is usually written for health care providers, so it may be difficult to understand. If it is, print out the information to discuss with your doctor.

Also included is the criteria you must meet to be eligible for the trial, such as the stage of disease, sites of metastasis, overall health requirements and previous treatments.

Contact information for the clinical trial investigators, staff or sponsors may be listed. These are resources who may be able to provide more details and answer questions about the study.

The sponsor is listed. This is the entity responsible for the clinical trial. It may be a pharmaceutical or biotechnology company, a university, the National Cancer Institute or others.

NEXT STEPS

Once you find a potential trial, talk with your doctor about how it may fit in with your treatment goals. Keep in mind that you may not qualify for every trial that interests you, and some may be closed. Also, look more than once. Trials are beginning and ending all the time, so put a reminder on your calendar to check back frequently. ■

Many factors are considered to create the best course for you

Treating **hepatocellular carcinoma (HCC)**, a type of liver cancer, is a coordinated effort among many skilled and caring professionals. Though research continues to produce more options for treating HCC, it is important to realize that treatment does not always mean “cure.” However, progress is still being made that is leading to longer, better lives for people who have HCC. Learn, ask questions and be informed so you can contribute to making the important decisions ahead.

You will work closely with a multidisciplinary team of specialists who will treat your HCC as well as any underlying conditions that caused it (see *Meet Your Health Care Team*, page 12). As a result, many things must be taken into consideration, including the following:

- How much of the liver is affected, including the number of tumors, tumor size and location
- Whether the cancer has spread (metastasized) outside the liver
- How well the liver is working and whether noncancerous areas remain healthy
- Comorbidities (other serious health conditions) you have
- Your overall physical condition
- Your preferences about quality of life

A thorough health assessment will be performed and more tests may be ordered before any recommendations are offered. As you and your medical team discuss how to move forward, it is very important that you agree about the goal of treatment. Ask about the treatments that may be helpful to you and about the side effects that you can generally expect with each. Be honest about your feelings toward those treatments and about your expectations for managing them on a daily basis.

Also, keep in mind that over time your treatment goals may change. Some goals to

think about include the following:

- Opting for curative treatment, which means eliminating the cancer
- Downstaging the tumor, which includes shrinking the tumor(s) to make liver resection or transplantation possible
- Slowing the cancer’s growth or progression to extend life
- Using supportive (or palliative) care to improve your quality of life, either by minimizing or managing side effects during treatment, treating post-operative pain and symptoms, or helping relieve pain and discomfort without active treatment

COMMON TREATMENTS FOR HCC

Your medical team will likely talk with you about one or more of the following options after diagnosis and at various times throughout treatment.

Surveillance, also called watchful waiting, may be recommended for tumors that appear to be growing very slowly. Postponing treatment while doctors closely monitor you (every 3 months is common) allows you to avoid potential side effects for as long as possible and for your doctors to watch for signs the cancer has returned. Regularly scheduled follow-up appointments that include imaging tests and blood tests will be necessary. It is very important to make and keep these appointments because treatment

should begin if the pace of cancer progression increases.

Clinical trials are a valuable treatment option that deserve serious consideration, especially if you are diagnosed with advanced HCC. These medical research studies may provide access to new therapies or combination therapies that are not yet available outside of a clinical trial. Ask your doctor if you should consider a clinical trial immediately after diagnosis or at any other time during your treatment (see *Clinical Trials*, page 7).

Surgery is the primary curative method for treating HCC. Liver surgery 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 surgical procedures for liver cancer. Do not hesitate to get 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 margin of healthy tissue. The remaining healthy organ will continue to function as it regenerates (regrows), often to near normal size. Surgical resection 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 must also be healthy enough to have surgery.

For minor resections involving easily accessible tumors, minimally invasive laparoscopic surgery may be performed. 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 transmitted to a video screen in the operating room to guide the surgeon. This method usually results in shorter recovery time, less blood loss and fewer post-surgery complications compared to open surgery.

More complex hepatectomies may be performed through traditional open resection with a large incision into the abdomen. This is major surgery and requires significant recovery time.

Liver transplantation is another highly effective potentially curative treatment for HCC. During the transplant, the entire liver is removed (hepatectomy) and replaced with a healthy liver, most often from a deceased



“SURVIVOR VOICE” / Anna W.

Being diagnosed with Stage III B liver cancer at 29 years old shocked Anna Webster. As a single mother with a 10-year-old daughter, she faced an uncertain future. After successful treatment, Anna now has no evidence of disease and shares the following advice for others affected by this difficult cancer.

- 1. Never go to appointments or scans alone.**
- 2. Seek a second opinion.** It brings confidence to decision making.
- 3. Find a research hospital that is at the forefront of liver cancer.**
- 4. Stay off the internet.** If you must search, take the information with a grain of salt.
- 5. Find and seek a support group.** Whether the support is on social media, at a hospital or in person, finding people you can relate to will help.

donor. In rare cases, transplant centers may suggest a living donor – typically a relative – though the criteria used to assess candidacy are not different than for using deceased donor livers.

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 and sodium, along with how well the liver makes factors for clotting blood. If your doctors believe you may be a potential candidate, you can be referred for assessment to a transplant center with extensive experience performing the procedure.

If you are deemed a candidate for a transplant, you will likely undergo bridging treatment while you wait for a liver to become available. Bridging therapy is designed to prevent the cancer from growing or spreading and may include ablation, embolization, radiation therapy or systemic drug therapy.

Radiofrequency ablation (RFA) therapy may be curative. It may be used to treat HCC when a tumor is unresectable or surgery is not an option for another reason. In this type of locoregional therapy, which focuses on the cancer’s location, this minimally invasive, image-guided procedure kills cancer cells by inserting a needle through the skin directly into the tumor and running electrical current through it to subject the tumor to extreme temperatures. Other types of ablation therapy include the following:

- Microwave ablation (MWA) uses microwave energy for the same purpose.
- Cryoablation, also called cryosurgery or cryotherapy, delivers extremely cold gas

through a hollow needle. This technique may be referred to as thermal ablation.

- Percutaneous ethanol injection (PEI), also called alcohol ablation, delivers alcohol directly into the tumor.

Embolization procedures, though not curative, can extend life and improve quality of life:

- A minimally invasive, image-guided procedure, chemoembolization 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.
- Transarterial embolization (TAE) 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. 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. Healthy liver tissue continues to receive blood from other blood vessels.
- Transarterial chemoembolization (TACE) is a similar procedure, but with the blood supply temporarily blocked, chemotherapy drugs can be delivered through the hepatic artery to the tumor and remain trapped there for a longer period of time.
- Radioembolization, also called 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 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 at different times throughout treatment to manage HCC. It is systemic therapy, which means the drugs travel throughout the body. Different forms of drug therapy may be used.

Molecularly targeted therapy is designed to slow the cancer’s progression. For this type of treatment, targeted therapy 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 common type of targeted therapy approved for use with HCC is called an angiogenesis

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)

As of 10/22/21

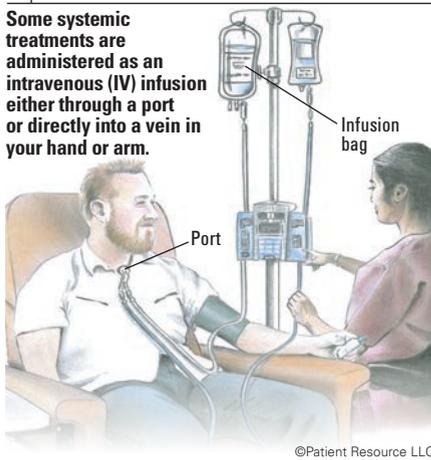
inhibitor. It works by blocking the growth of new blood vessels that feed the cancer cells. Blood vessels deliver nutrients the tumors need to grow and spread, so by shutting down the formation of new blood vessels, angiogenesis inhibitors in effect “starve” the tumor. Other targeted therapies treat mutations in the neurotrophic tyrosine receptor kinase (*NTRK*) (pronounced EN-track) gene, which cause cancer cells to grow. 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. Training the immune system to respond to cancer has the potential for a more lasting response that can extend beyond the end of treatment. Immune checkpoint inhibitors are the type of immunotherapy currently approved to be used for advanced HCC in certain instances. They travel throughout the body targeting proteins (PD-1 and PD-L1) on the surface of specific immune system cells. By blocking these proteins, immune checkpoint inhibitors prevent tumors from slowing down the immune response and thereby allow the immune cells to continue fighting the cancer. This type of immunotherapy is given intravenously (IV). Immunotherapy may be used alone or combined with another immunotherapy. It may also be used with targeted therapy.

Radiation therapy is another type of locoregional therapy. It uses high-energy X-rays or other types of radiation to destroy cancer cells. The goal of radiation therapy is to shrink tumors or slow their growth. Different forms of external-beam radiation therapy (EBRT) may be used as adjuvant treatment following surgery. EBRT may also be used in palliative care to relieve pain and other cancer symptoms by shrinking tumors. ■

SYSTEMIC THERAPY

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



Hope is stronger than fear

Greg Schiltz was diagnosed with hepatocellular carcinoma in 2016 and unfortunately passed away in 2020. His goal was to reach his 70th birthday, and he made it by 6 days. Throughout his journey, Greg and his wife, Sarah, chose to celebrate every day. Today, Sarah continues to be involved in the liver cancer community and shares their story to help others whose lives are affected by liver cancer.



Greg had hepatitis C but was asymptomatic for years.

Because the side effects of treatment were hard to handle, his primary care physician recommended not treating it. Then a new class of drugs came out, and Greg was intrigued. We found a gastroenterologist who prescribed a new drug that cleared the hepatitis C. However, in a routine follow-up, an ultrasound showed that Greg had hepatocellular carcinoma (HCC).

We began searching for a liver specialist, and though it took more time than we would've liked, we were thrilled with her. After reviewing Greg's case, she felt a liver transplant would give him the best odds. Greg was 67 and otherwise healthy, so he began a tremendous amount of testing to see if he was a candidate. They checked him out top to bottom, all the way to his dental health and mental health. They wanted to make sure he would be a good shepherd for the new liver he could be getting.

Greg was added to the transplant list, and we were told the wait could be long. In the meantime, he had chemoembolization and radiation therapy to help ensure the tumors in his liver didn't grow out of control, causing him to become ineligible for a transplant.

Greg's doctor suggested we "multi-list," which meant not limiting Greg's transplant possibilities to just the one center. To get on the list at another cancer center, he needed to go through their extensive testing requirements just as he'd done at the first center. We selected a second center across the country that was known for performing frequent liver transplants, and it was that cancer center that called soon after and told us he was number one on the list.

Excited, we moved across the country, taking my sister and her husband with us for support. We soon discovered patience is essential in the transplant world. We got our hopes up four times. The first time, the harvested liver was no good. The second time, the liver was not the right size. The third time, Greg was the backup patient. They always prepped a backup patient in case the

primary patient couldn't take the liver for some reason. However, this liver worked for the primary patient. The fourth time, the liver was too cirrhotic.

During this time, he had a number of chemoembolizations to keep the tumors at bay. Eventually, the tumors grew out of transplant criteria and he was taken off the list. A transplant was no longer an option. Greg was given a prognosis of six months. We went home and started on his bucket list.

But, that six months turned into three and a half years, thanks to a clinical trial testing a novel combination drug therapy and then a newly approved targeted therapy.

We went to Maui a couple of times, and we added to our fur baby family. A lifelong surfer, Greg always wanted a Woody Wagon. He bought a '47 Woody that we named Woodrow. Our dream of living on the beach wasn't practical since we had to be close to medical facilities so instead, we remodeled, giving our home a beachy feel, complete with a whimsical art studio in the backyard where Greg could paint.

Sometimes it was difficult, but I decided I wouldn't let the fear consume me. I had considered stepping down from work, but the company I work for was very supportive. I was able to work remotely, and it was a healthy distraction. And, truthfully, I think I would have driven Greg crazy if I didn't have something else to focus on! I found solace in therapy and support groups.

We had a 25-year love story. I wish it would have been more, but I'm grateful for our wonderful friendship and marriage. As an homage to everyone who helped us, I am a mentor through cancer support groups such as Imerman's Angels, Inspire and Blue Faery. I am a patient advocate for the NCI Task Force for Liver Cancer, with a focus on clinical trials, something that made a big difference in our lives. I'm also on the board of Cancer U, and I give presentations for pharmaceutical companies and cancer agencies such as the American Liver Foundation. ■

When I share our story, I always offer these insights:

1 / Find the right team of doctors and the right cancer center for you. Interview them. Find out what motivates them and where they get their information.

2 / You are the captain of this ship. Share your priorities about your preferences for treatments and quality of life.

3 / Don't take for granted that all your doctors and cancer centers communicate with each other. All electronic health records are not integrated.

4 / Assemble your support system. You may not know anyone who's had liver cancer. Seek out online support groups for liver cancer and transplants.

5 / Hope is stronger than fear. New treatments are coming. Don't ever give up.

better off bald

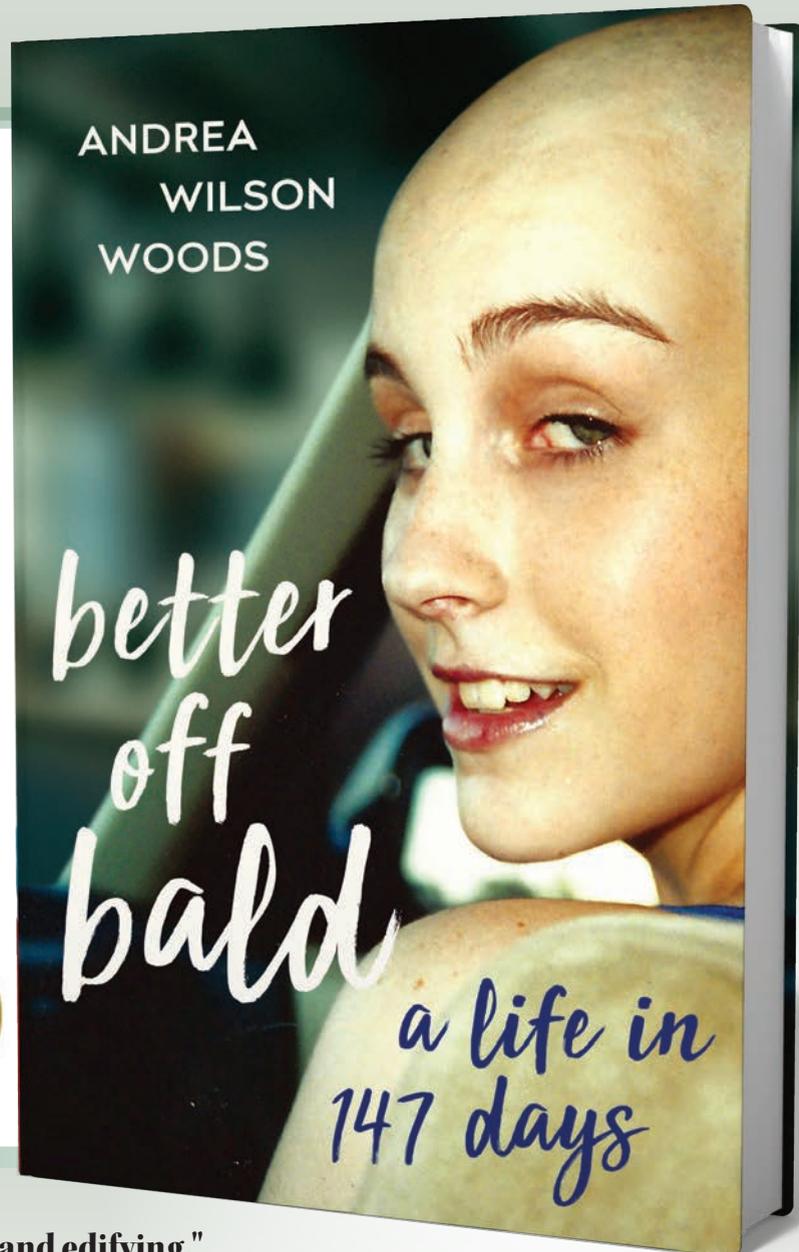
a life in 147 days

by ANDREA
WILSON WOODS

Facing the fight of her life after a diagnosis of advanced liver cancer, Adrienne Wilson squeezes more life into 147 days than most do in a lifetime.

"*Better Off Bald* is a raw story about two sisters, one a teenager and the other barely an adult, facing cancer. Andrea Wilson Woods works hard to be the grown-up and a mother to her younger sister, Adrienne, when the diagnosis of cancer crashes down on them. Ms. Wilson Woods holds nothing back and delivers a story that at times feels like you are on a roller coaster ride with these two sisters as they try to stay on track with life. *Better Off Bald* will jolt you emotionally and hopefully inspire all medical professionals to do a little better, and all patients to fight a little harder."

~ Nicholas Borys, MD, Executive VP and Chief Medical Officer of Celsion Corporation



"Devastating and heartbreaking, inspiring and edifying."

~ Pacific Book Review

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

~ Literary Titan

Available now → betteroffbald.com

10 things to know about being a caregiver

Your hard work and support can make a world of difference to a loved one diagnosed with liver cancer. Attending medical appointments, managing medications, running errands and offering emotional support are just some ways you may help. As you prepare to take on these important responsibilities, consider the following suggestions.

1 Get the “OK” to receive medical information. Be sure you are authorized to communicate with your loved one’s health care team, access medical information, renew prescriptions and more. If you are unsure about the forms you may need to sign, ask a member of the health care team.

2 Meet the health care team. Introduce yourself to the doctors, nurse navigator and other key people on the team. Ask questions to help you learn about your loved one’s diagnosis, treatments and unique needs. Determine the best ways and times to contact the team. Building strong relationships will make it easier to communicate openly and honestly with them.

3 Recognize and report symptoms and side effects. It is often difficult for people undergoing cancer treatment to accurately remember and describe symptoms to their doctors. Track symptoms at home with detailed notes to take to appointments along with a running list of questions. Speak up to help clarify details about the frequency, intensity and duration of side effects. Before treatment begins, find out what symptoms should warrant a call to the doctor, a visit to urgent care or emergency medical attention.

4 Keep track of the calendar. Maintain a paper or electronic calendar or one on your phone to track medical appointments and lab tests.

5 Help manage cognitive and physical limitations. An HCC diagnosis and treatment can affect your loved one’s mental focus, memory, thinking skills, emotional stability and stress level — all of which can significantly impair communication skills.

6 Explore telehealth. Find out if your loved one’s medical team offers virtual visits and if they are covered by insurance. This option enables your loved one to stay home if he or she feels unwell or finds it physically challenging to go to an appointment. It is more convenient for people who live far from the medical office, helps limit potential exposure to infections in clinics and hospitals, and offers an easy way to report symptoms or complications between visits.

7 Serve as “Information Central.” You and your loved one can get exhausted as family and friends call with questions about what the doctor said, what the treatment plans are, how the patient is

feeling and how they can help. Create an email group so you can send one email with all of the information your loved one is comfortable including. This will dramatically reduce phone calls and individual emails as well as ensure that everyone is getting the same information and at the same time. Siblings, for example, are informed all at once rather than one being communicated with first.

8 Be a good listener. Facing HCC can be overwhelming, and sometimes your loved one may just need someone to talk to. Simply listening is more helpful than you may realize.

9 Take care of yourself. You will be a more effective caregiver if you maintain your own health. Eat right, exercise, keep medical appointments and give yourself time off. Take advantage of family and friends who offer help. Create a list of things that can be delegated to others. People want to help, and you must realize you can’t shoulder all the responsibility alone.

10 Find online support groups and resources. Taking on the role of a caregiver can be challenging, but you do not have to do it alone. There are many resources for the physical and emotional aspects of being a caregiver, including how to manage the stigma of HCC. See the resources in *Assistance*, page 17, and/or ask your health care team for referrals. ■

Meet Your Health Care Team

➔ *People with liver cancer may consult with multiple doctors, specialists and other health care professionals. Some of the following may be on your team.*

- ▶ **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. The surgeon replaces a diseased liver with a healthy one.
- ▶ **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 chemotherapy for cancer patients.

- ▶ **Palliative care specialists** work to provide physical and emotional relief for 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; they may also be patient advocates, helping identify barriers to treatment such as the need for transportation or help with copays and deductibles, and access resources to resolve such barriers. Navigators are commonly involved throughout the continuum of care.
- ▶ **Radiation oncologists** treat cancer using radiation therapy.
- ▶ **Surgical oncologists** have special training in performing biopsies and other surgical procedures in cancer patients.
- ▶ **Other specialists** to address other health conditions.





The Story behind the Blue Faery



➔ **When 15-year-old Adrienne was diagnosed** with Stage IV liver cancer, her sister and parent Andrea Wilson Woods was devastated. She had raised Adrienne from the time she was eight. As her legal guardian, Andrea had to make major decisions about Adrienne’s treatment plan. Unfortunately, Andrea had no one to guide her. Together, they did the best they could on a journey that lasted 147 days, and the experience changed the course of Andrea’s life.

“Any type of cancer diagnosis is shocking, but being unfamiliar with liver cancer made it more challenging,” Andrea said. “At the time, information about liver cancer wasn’t easy to find, even among medical professionals. I quickly learned how complex liver cancer is.”

Andrea grappled with how her teenage sister – a young Caucasian female who had never been outside the U.S. – had a disease that typically affected non-North American men over the age of 50. Andrea was forced to make treatment decisions she felt unprepared to make.

“I trusted my gut, and I fought fiercely for the best care available. Watching Adrienne face her illness was heartbreaking, yet she handled it better than any adult would have. Her courage, dignity, grace and humor inspire me every day. We made some fantastic memories. She met her favorite musician, Dave Navarro of Jane’s Addiction, twice!”

In the short time between Adrienne’s diagnosis and passing, Andrea learned a great deal about how to be an advocate for someone with cancer.

“I wanted to share what I’d learned with others because I didn’t want anyone else going through what we did. And though it was never my childhood dream to one day start a nonprofit organization, Blue Faery was born.”



The mission of Blue Faery: The Adrienne Wilson Liver Cancer Association is to prevent, treat and cure primary liver cancer, specifically hepatocellular carcinoma (HCC), through research, education and advocacy. Every year on Adrienne’s birthday, the organization gives out its Blue Faery Award for Excellence in Liver Cancer Research, which recognizes innovative, HCC-specific, cutting-edge research.

For patients and caregivers, Blue Faery has free educational materials in multiple languages, a private online HIPAA-compliant community, a peer-to-peer support program and even opportunities for patients to receive free precision cancer analysis reports. Earlier this year, Blue Faery conducted its first public awareness campaign to spread awareness and increase the prevention of liver cancer and disease.

People often ask Andrea about the origin of the charity’s name. “Adrienne always loved faeries, and her favorite color was blue. She dyed her hair bright blue before starting high school. Later, she purchased a pair of blue butterfly wings that she wore on her back on special occasions. When she started chemotherapy and lost her hair, she asked for a bright blue bobbed wig so she could maintain her look. She was our original Blue Faery.”

On rough days, Andrea takes comfort in knowing that she gave Adrienne a good death. She feels Adrienne’s spirit is always with her.

“When we started Blue Faery, our goal was to put ourselves out of business. We want to get to the point where our services are no longer needed because liver cancer no longer exists. My greatest desire is to see a cure for primary liver cancer in my lifetime.” ■



(Left to right): Summer 1995; August 2001 Make-A-Wish event; August 2001 PAWS program

Rely on your medical team to manage potential side effects

F *Feeling nervous or concerned about potential side effects* is normal. It may reassure you to know that there are many ways to prevent and manage side effects related to treatment. Knowing what to expect can help you prepare. When you discuss treatment options with your doctor, ask about the possible side effects for each option and when they are likely to occur.

Preventing and managing them is also extremely important for the success of your treatment. That means you have an important role in side effect management, too. Keep the lines of communication open with your health care team and let them know as soon as a symptom or side effect occurs. That enables them to address it early, hopefully before it gets worse. Also, be honest with your family and caregiver about the side effects you have and their level of severity.

POTENTIALLY SEVERE SIDE EFFECTS

Though serious side effects are rare, they can occur with certain types of treatment. Ask your doctor whether you are at risk from the therapies in your treatment plan, how to identify the symptoms and when to seek emergency care. Report symptoms immediately if they occur 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 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, paracentesis (procedure to drain the fluid), chemotherapy or surgery. Your doctor will discuss the option that is best for you.

- 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 for symptoms to watch for and when to go to the emergency room.
- Infection can occur as a result of a low white blood cell count (neutropenia) or other factors. 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. Some irAEs can 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.

SOME COMMON PHYSICAL SIDE EFFECTS

Most cancer treatments have physical side effects, but you likely will not experience all of them (see Table 1, page 15). People respond differently, even if they have the same diagnosis and type of treatment.

Be prepared for late effects. These are side effects that develop weeks, months or years after treatment ends. They can vary widely from person to person based



Draw on the valuable support of palliative care

► **During HCC treatment, you may experience complications as the disease progresses.**

This may require additional support and assistance from your multidisciplinary health care team. To be most effective, team members draw on a broad range of services known as palliative care. Also known as a form of supportive care, it addresses the physical, emotional, practical, spiritual, financial and family-related challenges of people diagnosed with cancer and their loved ones.

These services are designed to benefit anyone with a serious or life-threatening illness, from diagnosis 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.”

It is recommended that you seek palliative care assistance soon after diagnosis because the course of HCC is difficult to predict. As liver function decreases, toxins that are normally filtered by the liver can build up, which can cause cognitive decline and other conditions that may make it difficult to think clearly. You may need assistance to understand the prognosis and make decisions about treatment and quality of life.

To begin, ask your doctor for a palliative care referral. Together with a palliative care specialist, you will develop a plan to ease symptoms and improve your quality of life. A specialist may offer

the following forms of support:

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

The palliative care team may include palliative care 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, you can talk with the hospital’s social worker or financial counselor or your health insurance representative.

on many factors, such as age, gender and overall health status. Because they are hard to predict, knowing what to do if they occur is a good idea. Talk with your doctor about the symptoms to be the most concerned about.

PREPARING FOR EMOTIONAL EFFECTS

A cancer diagnosis can cause feelings of distress that affect your mental, physical, social and spiritual being. It is common to experience a range of emotions, from sadness and anger to anxiety and depression as well as loneliness and regret. These feelings, and all others you experience, are valid. It is normal to be concerned about how cancer treatments will affect your health, family and daily life.

Support is available to ensure your whole person is being cared for. You do not need to face these emotional challenges alone. These suggestions may help:

- Understand that your feelings are normal.
- Staying positive is important, but it is just as important to give yourself permission to feel bad, mad or sad sometimes.
- Cancer survivors are valuable resources for support, friendship and insight. Ask about local or online support groups or phone-based peer support programs.
- Explore meditation, gentle yoga, massage therapy, deep breathing exercises or other relaxation techniques.

Taking care of your emotional well-being will help you handle the challenges of cancer treatment. Consider addressing these feelings with the following resources:

- A counselor, psychologist, psychiatrist, nurse or another specialist.
- Support groups. Some offer one-on-one buddy programs that pair you with another person who has the same type of cancer as you. Talking with someone who has gone through a similar experience can be invaluable. In addition, telephone and email cancer helplines and advocacy groups are available.
- Exercise. It may reduce anxiety and depression. Research shows that regular exercise can greatly improve mental health at any time during treatment. Even if you were not active before being diagnosed with HCC, a customized exercise program can be a benefit.

You may also have scanxiety, 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. In addition to the previous suggestions for relieving anxiety, set expectations with your doctor or nurse about when and how you will receive the results so you are not left waiting and wondering.

Remind yourself that it is normal to feel this way. Consider discussing your fears with your friends, a support group or a therapist. Keep your mind occupied with things you

enjoy, such as reading, playing games or gardening. Staying busy gives you less time to worry.

If you or your caregiver notices any of the following symptoms, notify the health care team:

- The inability to follow treatment due to extreme emotional distress.
- Constant thoughts of death or feelings of hopelessness.
- Becoming unusually angry or irritable.
- Withdrawing and isolating yourself from family and friends.
- Feeling worthless or thinking of suicide. ■

TABLE 1
▲ **SOME COMMON SIDE EFFECTS**

Side Effects	Symptoms
Abdominal pain	Cramping and dull aches in the abdominal area
Ascites	Fluid accumulation in the abdomen
Bleeding problems	Hemorrhaging and bruising
Chemo brain	Brain fog, confusion and/or memory problems. Also known as cognitive dysfunction
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
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and 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
Mouth sores	Inflammation in the mouth with blister-like ulcers
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	Gaining or losing weight

Prepare for a promising future with a follow-up care plan

Whether you are still in treatment or have finished, it is important to continue to be proactive about your health, including making and keeping follow-up appointments. Regular monitoring will help your doctor manage any long-term side effects and detect warning signs of a recurrence or a second cancer so early treatment is possible. These appointments also give you the opportunity to continue communicating with your health care team as you transition back into former activities and explore new ones.

Your doctor or nurse will work with you to develop a customized follow-up care plan that may include the following:

- Appointment schedule for ongoing monitoring
- Palliative care for physical and emotional side effects
- Medications or therapies, including type, dosage, frequency and duration
- Referral(s) for cancer rehabilitation services, 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
- Other things you can do to stay healthy

All of the detailed information you share with your doctor can be vital. Be sure to tell your doctor how you are feeling physically, mentally and emotionally, and include the following:

- New or ongoing pain that is not adequately relieved
- New or ongoing physical symptoms,

- including leg swelling, abdominal distention, jaundice, weight loss or gain, bladder/bowel control; deep fatigue or insomnia; sexual dysfunction or lack of desire; mobility issues; signs of infection; tingling or numbness; fluid buildup; or changes in appetite, sense of taste, vision or hearing
- Cognitive (thinking-related) symptoms, such as difficulties with memory, concentration, processing information, word-finding or completing tasks
- Emotional issues, including depression, anxiety, fear, anger, grief, hopelessness, emotional numbness, feeling overwhelmed or other concerns
- New medications, over-the-counter remedies, vitamins, supplements or herbs
- Visits to the emergency room, urgent care or other doctors, even if not cancer-related
- Homeopathic or naturopathic therapies

How often you see your doctor depends, in part, on your unique diagnosis and the chance of recurrence. It also depends on your overall health. Continue to keep copies of your medical records. That is especially helpful if you see a new doctor.

MOVING INTO SURVIVORSHIP

Once active treatment ends, you will enter a new phase known as survivorship. The term “survivor” means different things to different people. For the purposes of this article, survivor refers to anyone who has lived with, through or beyond cancer and is disease-free or living with cancer.

To assist with the transition, your doctor may recommend a survivorship care program. Although doctors are not required to give you a survivorship care plan, many cancer centers provide survivorship educational programs about ongoing care.

This plan is designed to keep track of all pertinent information about your care and to guide you moving forward. The information may include your medical history, which may contain diseases, conditions or disorders, surgeries and treatments, hospitalizations, pregnancies, lab reports, test results and ongoing health medications; a list of health care team members with contact information; your specific diagnosis, including type, subtype, stage and date of diagnosis; and pathology and consultation notes. It may also include the tests you may need after treatment.

If you do not receive a survivorship plan from your doctor, ask your nurse navigator or case manager to help you. Or, create your own. Download a sample Survivorship Care Plan at PatientResource.com/SurvivorshipPlan.aspx, then request copies of all of your tests, biopsies, surgeries, pathology and consultation notes from your doctor’s office. ■

Pay attention to over-the-counter medications

As an essential part of the digestive system, the liver performs critical functions such as filtering the blood, processing and storing nutrients, converting nutrients into energy, removing toxins and maintaining proper sugar levels.

Many people with liver cancer already have some level of damage to their liver, so preventing further damage to it will be crucial. That includes being careful about the medications and supplements you take in order to prevent interference with medications prescribed by your physicians or toxicity to your liver.

Your doctor may advise you to avoid or reduce the use of an over-the-counter medication called acetaminophen. It is known to

cause liver damage if taken in large quantities with compromised liver function, can interact with other medications and increase side effects. It is frequently used for headaches and other common ailments, but you may not be aware that it is a very common drug ingredient in many prescription and over-the-counter medications. These include generic and store-brand pain relievers, fever reducers and sleep aids as well as cough, cold and allergy medicines. It may be easy to take too much without realizing it if you are using multiple products containing this active ingredient. A list of active ingredient names can help you identify these drugs. Ask your doctor if 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 doctor 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.”
- Check with your pharmacist every time you start, stop, change or fill a prescription.
- Take your medicine 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 medicine that has expired.
- Do not take or share medicines with others.
- Always keep a list of your current medications with you.
- Take your medications with you when you travel.

Support and financial resources available for you

CANCER EDUCATION

American Cancer Society www.cancer.org
 American Society of Clinical Oncology www.cancer.net
 Cancer University www.cancer.university
 Centers for Disease Control and Prevention (CDC) www.cdc.gov
 Get Palliative Care www.getpalliativecare.org
 National Cancer Institute www.cancer.gov, 800-422-6237
 National Comprehensive Cancer Network (NCCN) www.nccn.org
 OncoLink www.oncolink.org
 Patient Resource www.patientresource.com

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program www.4thangel.org
 Cactus Cancer Society www.cactuscancer.org
 CanCare www.cancare.org
 Cancer and Careers www.cancerandcareers.org, 646-929-8032
 Cancer Care www.cancercare.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.cancerreallysucks.org
 Cancer Support Community www.cancersupportcommunity.org, 888-793-9355
 Cancer Support Community Helpline 888-793-9355
 Cancer Survivors Network csn.cancer.org, 800-227-2345
 Caregiver Action Network www.caregiveraction.org, 855-227-3640
 CaringBridge www.caringbridge.org
 Center to Advance Palliative Care www.capc.org
 Chemo Angels www.chemoangels.com
 Cleaning for a Reason www.cleaningforareason.org
 Connect Thru Cancer www.connectthrucancer.org
 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, 216-455-1517
 Guide Posts of Strength, Inc. www.cancergps.org, 336-883-4483
 Imerman Angels www.imermanangels.org, 866-463-7626
 LivingWell Cancer Resource Center www.livingwellcrc.org, 630-933-7860
 Lotsa Helping Hands www.lotsahelpinghands.com
 The Lydia Project www.thelydiaproject.org, 877-593-4212
 MyLifeLine mylifeline.org
 National LGBT Cancer Project www.lgbtcancer.org, 212-673-4920
 Patient Empowerment Network www.powerfulpatients.org
 SHARE Caregiver Circle www.sharecancersupport.org/caregivers-support, 844-275-7427
 Well Spouse Association www.wellspouse.org, 732-577-8899
 weSPARK Cancer Support Center www.wespark.org, 818-906-3022
 Wigs & Wishes www.wigsandwishes.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, 800-422-6237
 NCI Cancer Information Service 800-422-6237
 WCG CenterWatch www.centerwatch.com, 866-219-3440

INSURANCE PREMIUM EXPENSES

Cancer Care Co-Payment Assistance Foundation www.cancercarecopay.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
 Patient Services, Inc. www.patientservicesinc.org, 800-366-7741

LIVER CANCER

American Liver Foundation www.liverfoundation.org
 Blue Faery: The Adrienne Wilson Liver Cancer Association www.bluefaery.org
 Cancer Experience Registry (Cancer Support Community) www.cancerregistryexperience.org
 Global Liver Institute www.globalliver.org

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

NUTRITION

American Cancer Society www.cancer.org, 800-227-2345
 Cancer Support Community www.cancersupportcommunity.org, 888-793-9355

LLS | PearlPoint Nutrition Services www.pearlpoint.org, 877-467-1936
 OncoLink www.oncolink.org
 Physicians Committee for Responsible Medicine www.pcrm.org/health-topics/cancer

PRESCRIPTION EXPENSES

America's Pharmacy www.americaspharmacy.com, 888-495-3181
 Cancer Care Co-Payment Assistance Foundation www.cancercarecopay.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.medicinassistancecoteol.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

Avastin Patient Assistance www.avastin.com/patient/support/financial-resources, 866-422-2377
 Bristol-Myers Squibb bms.com/patient-and-caregivers/get-help-paying-for-your-medicines.html, 800-721-8909
 Bristol-Myers Squibb Access Support bmsaccesssupport.bmscustomerconnect.com/patient, 800-721-8909
 Bristol-Myers Squibb Patient Assistance Foundation bmspaf.org, 800-736-0003
 Cabometyx EASE www.cabometyx.com/financial-support, 844-900-3273
 Cyramza Financial Support lillyoncologysupport.com/cyramza-financial-support, 866-472-8663
 Eisai Reimbursement Resources www.eisair reimbursement.com/patient, 866-613-4724
 Genentech Access Solutions genentech-access.com/patient, 877-436-3683
 Genentech BioOncology Co-pay Assistance Program copayassistancenow.com, 855-692-6729
 Genentech Patient Foundation gene.com/patients/patient-foundation, 888-941-3331
 Keytruda KEY+YOU www.keytruda.com/key-you-sign-up, 855-398-7832, press 2
 Keytruda Patient Assistance merckaccessprogram-keytruda.com/hcc/, 855-257-3932
 Lenvima 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 merckaccessprogram.com
 Merck Helps merckhelps.com, 800-727-5400
 Nexavar Access www.nexavar-us.com/access-services-by-bayer, 800-288-8374
 Opdivo with You patientsupport.bmscustomerconnect.com/opdivo-with-you-registration, 855-673-4861
 Rozlytrek Access Solutions genentech-access.com/patient/brands/rozlytrek, 877-436-3683
 Stivarga Bayer Access Services www.stivarga-us.com/access-services-by-bayer, 800-288-8374
 Tecentriq Access Solutions genentech-access.com/patient/brands/tecentriq, 877-436-3683
 Tecentriq Patient Assistance www.tecentriq.com/hcc/patient-support/financial-assistance, 866-422-2377
 Vitakvi Patient Assistance www.vitakvi-us.com/patient-assistance-program, 800-288-8374
 Yervoy Patient Access www.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
 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
 Angel Flight Central www.angelflightcentral.org, 866-569-9464
 Chai Lifeline www.chailifeline.org, 877-242-4543
 Compass to Care www.compasstocare.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, 877-563-7498
 Lifeline Pilots www.lifelinepilots.org, 800-822-7972
 Mercy Medical Angels www.mercymedical.org
 Operation Liftoff www.operationliftoff.com
 Patient Access Network Foundation www.panfoundation.org, 800-394-0161
 Patient AirLift Services www.palservices.org, 888-818-1231

➔ For more resources, go to PatientResource.com

This patient education guide was produced with support from:

