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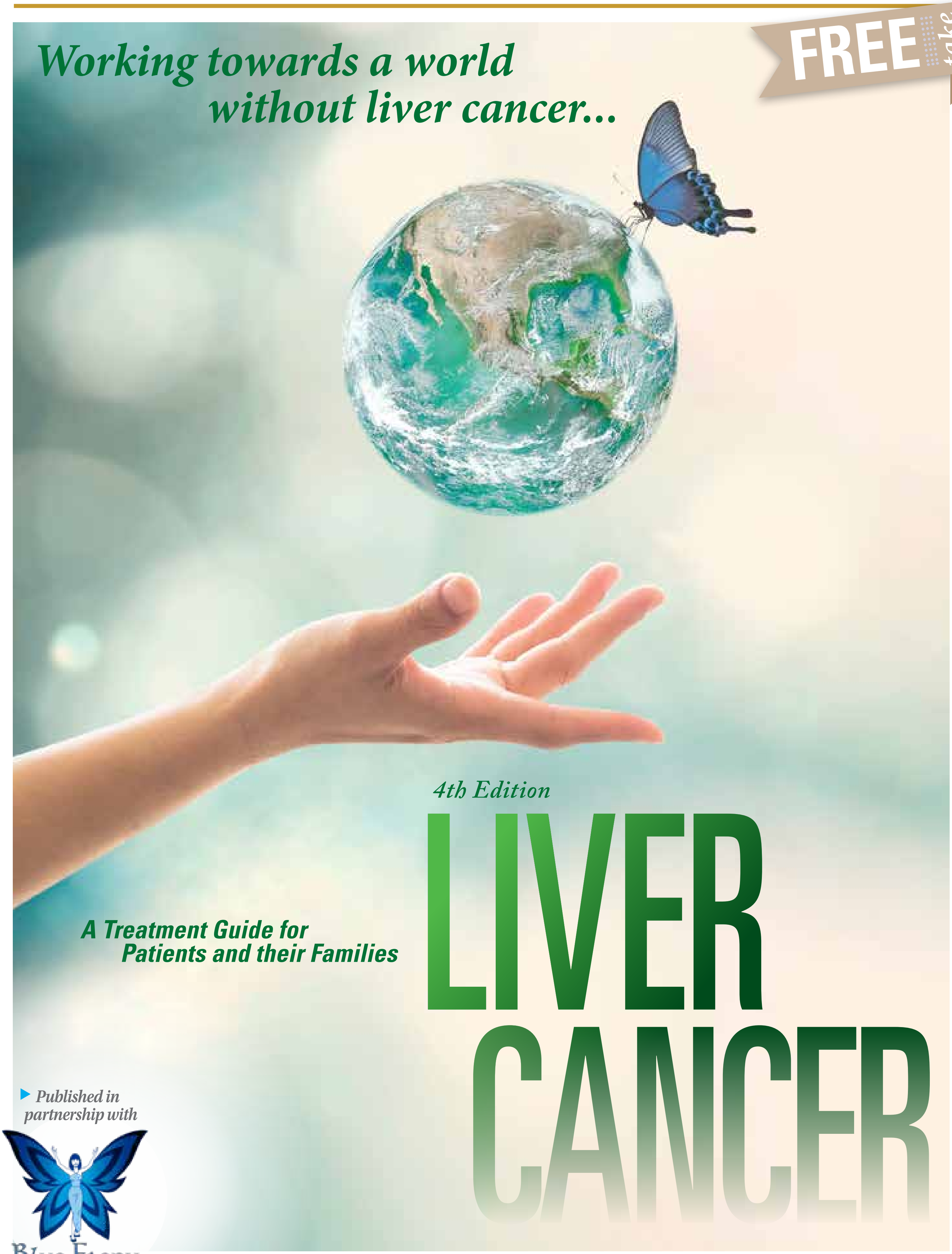

4th Edition

LIVER CANCER

A Treatment Guide for Patients and their Families

Published in partnership with

Blue Faery
The Adrienne Wilson Liver Cancer Association

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HealthUnlocked

LIVER CANCER COMMUNITY

A safe, online, HIPAA-compliant community for HCC patients and families available in English, Spanish, and Portuguese.

About the Community

- 712 members
- 400+ posts
- 1,600+ replies
- 17% participation rate
- 1 to 1 patient to caregiver*
- **Top category:** Information & Support
- **Common needs:** finding others with shared experience, feeling anxious, accessing help

*For those who self-identify; people may sign up anonymously

4th Edition

LIVER CANCER

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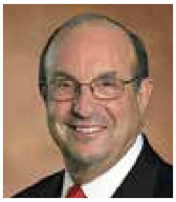

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Find community and knowledge along the way

Living with liver cancer requires strength, and you should not expect to handle it on your own. The good news is you do not have to. The liver cancer community is made up of a variety of experts, organizations and people just like you who are dedicated to helping you live your best life with a liver cancer diagnosis.

Primary liver cancer is a disease in which cancer cells initially form in the tissues of the liver. It 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. Cancer that begins in other parts of the body and spreads to the liver is not considered liver cancer. Cancer that spreads from elsewhere to the liver is called a metastasis (e.g. colon cancer metastasis).

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

THE ROLE OF THE LIVER

To understand HCC, it helps to know more about your liver:

- It is the largest organ in the body, with two lobes in the upper right side of the abdomen (see Figure 1).
- It performs many functions, including supporting detoxification, digestion, immunity, metabolism, normal blood clotting and vitamin storage.
- It is the only organ in the body that has the ability to regenerate. For example, when part of the liver is removed, it has the ability to grow back — but only if it is healthy.

LEARNING ABOUT HCC

HCC begins in the hepatocellular cells of the liver tissue that are responsible for metabolic functions, detoxification and immune cell activation. Although it can develop in an otherwise healthy liver, it is much more often diagnosed in the presence of an underlying chronic liver condition. That is why it is referred to as “a disease within a disease.”

Several symptoms are associated with HCC, but most patients do not have any symptoms. In some cases of more advanced HCC, one may experience the following:

- Mild to moderate pain or tenderness in the upper right part of the abdomen or right shoulder
- Unintended weight loss
- Abdominal distention
- Decreased appetite
- Deep fatigue
- Vomiting

As HCC becomes advanced and spreads beyond the liver (most commonly to the lung, abdominal lymph nodes or bone), multiple tumors may develop. As a result, you may have these symptoms:

- Ascites (uh-SY-teez), swelling in the abdomen or legs
- Dark urine or light-colored stools
- Jaundice, causing yellow skin and yellowing in the whites of the eyes

RISKS AND CAUSES

People often want to know what caused their liver cancer diagnosis. It is not always a single reason. Cirrhosis is the most common underlying chronic condition of HCC. It is a progressive disease that causes inflammation and scarring. Scar tissue causes irreversible damage as it replaces healthy liver cells, causing the liver to gradually lose its ability to function. Cirrhosis itself is not reversible; however, steps can be taken to prevent it from becoming worse (see Table 1). The most common causes of cirrhosis are metabolic dysfunction-associated steatotic liver disease (MASLD), viral hepatitis (hepatitis B or C), and chronic excessive intake of alcohol.

Higher incidence rates of HCC are found in people over 60 and in Asians and Pacific Islanders, African Americans, American Indians/Alaska Natives and Hispanics. Studies attribute this to the fact that some minorities and socioeconomically disadvantaged groups do not have widespread access to surveillance and treatments. Research is also underway to explore other causes, such as higher rates of MASLD, diabetes and other risks. A variety of other factors may increase the risk for HCC. Some are lifestyle-related, but others – your genetic makeup, ethnicity and age – are completely out of your control.

Even though you cannot change certain characteristics about yourself, knowing the factors that may have contributed to your diagnosis can help you process your situation. It can also encourage your loved ones to take steps to reduce the risk factors that they can change (see Table 1).

MASLD, formerly known as nonalcoholic fatty liver disease (NAFLD), involves excess fat buildup in the liver. In its most severe

FIGURE 1

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 next to the stomach, protected by the ribs.

Along with playing a key role in the digestion of food, the liver performs many 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 that is diseased cannot regrow. This may limit surgical options for cancer treatment.

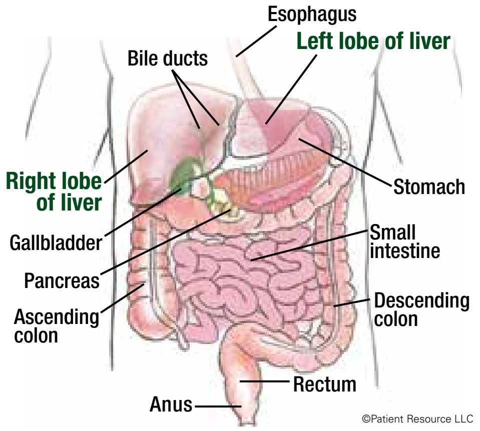

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TABLE 1

COMMON RISK FACTORS*

Condition or habit	Ways to reduce risks of chronic liver diseases
Heavy alcohol use	• Avoid or reduce consumption of alcohol. • Ask your care team for help stopping or reducing alcohol consumption.
MASH and MASLD	• Try to reach and maintain a healthy weight. • Exercise regularly. • Eat a well-balanced diet. • Manage existing health conditions, such as diabetes and high cholesterol. • Stop smoking. • If you drink alcohol, avoid or reduce consumption of it. • Talk to your care team about clinical trials. • Find a support group to learn from other people facing MASH.
Hepatitis B virus (HBV)	• Treat active HBV infections. Avoid contracting HBV via exposure to the blood of a person infected with HBV, contaminated needles or sexual transmission (unprotected sex). • Ask your care team for the HBV vaccine. It has a significant success rate for preventing hepatitis B.
Hepatitis C virus (HCV)	• Treat active HCV infections with direct antiviral agents (DAAs). • Avoid contracting HCV via exposure to the blood of a person infected with HCV or contaminated needles (used for IV drugs).
Excess body weight	• Eat a well-balanced diet. • Exercise regularly. • Try to reach and maintain a healthy weight. Excess weight can lead to fatty liver disease and diabetes, both of which are linked to liver cancer.
Tobacco use	• Stop smoking. • Ask your care team for help quitting.

Risk factors are in no particular order.

form, metabolic-associated steatohepatitis (MASH), formerly known as NASH, can cause cirrhosis, a progressive liver disease that replaces liver cells with scar tissue.

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

YOUR COMMUNITY AWAITS

Get to know the resources around you. They are available as soon as you receive your diagnosis, and they come from multiple areas.

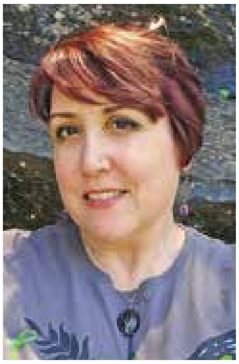
Your multidisciplinary care team involves your doctor and a mix of experienced health and psychosocial care professionals. The specific members of that team will depend on your diagnosis and your needs. They will work with each other and you to plan and manage your treatment. They are also a good resource for a second opinion. You are encouraged to get another opinion from a doctor who has extensive experience treating liver cancer. A second opinion enables you to validate the diagnosis you have been given and hear about other treatment options that may be available.

Case management is a program designed to help manage the practical issues associated with your diagnosis and treatment and reduce your stress and anxiety in the process. If your care team does not have a case manager on staff, ask for a referral.

Palliative care clinicians focus on reducing how aggressively cancer or its treatment causes symptoms or reduces your quality of life.

Advocacy and support groups put you in touch with other people who are familiar with what you are experiencing. Through Blue Faery, the Adrienne Wilson Liver Cancer Association, an advocacy group dedicated to preventing, treating and curing HCC, you will be introduced to programs such as the Liver Cancer Community, Love Your Liver, The Truth about Liver Cancer, and You and Liver Cancer. These programs are designed to give you and your loved ones a forum to learn and discuss the physical and emotional aspects of your diagnosis.

Your community is especially important if you, your loved ones or caregivers face the common issue of disease stigma. Unfortunately, it often goes along with this diagnosis because of the associated underlying conditions of the disease that are sometimes related to lifestyle choices. Do not let negative feelings weigh you down. Adopt a positive mindset and put your energy into managing this diagnosis. ■



"I'm a person who has cancer, not a cancer patient."

Read Kara's story on page 9.

Your role in preventing MASH

► **Metabolic dysfunction-associated steatohepatitis (MASH) is the name for liver inflammation and damage caused by a buildup of fat in the liver. Formerly referred to as NASH, it is a serious condition that can progress to a more severe form of fibrosis (liver scarring) called cirrhosis and eventually HCC.**

Although a cure for MASH is not available at this time, researchers are exploring ways to prevent it. Because screening for MASH is not common and symptoms can take years to develop, learning what you can do to help prevent it is vital (see Table 1).

Fat in the liver is normal until it becomes more than five percent of the weight of your liver. That is dangerous to your health because it makes it harder for the liver to carry out its many functions.

Along with the risk factors shown in Table 1, simply being an older adult, being overweight or obese with more body fat around the abdomen, high blood pressure and leading a sedentary lifestyle are contributing factors.

Most people with MASH have no symptoms. If MASH is suspected, your doctor may recommend a liver biopsy to definitively diagnose it. And your doctor may investigate:

- **Use of prescription and over-the-counter medicines that may increase the fat in your liver.**
- **Amount of alcohol consumption.**
- **Diet.**
- **Physical activity.**
- **Medical history and health conditions.**
- **Physical exam results.**
- **Blood test results that check liver enzymes, fibrosis and blood fats, such as cholesterol.**
- **Hepatitis B and C test results.**
- **Imaging test results that measure liver stiffness, which indicates fibrosis.**

Understanding the risk factors that apply to you is the first step in taking control of your health. Use the resources in this guide to connect with support groups. It is easier to make major lifestyle changes with other people who have the same goal.

Staging is the first step to planning for treatment

Staging usually occurs right after diagnosis. The process requires results from physical exams, blood tests, imaging studies and biopsies. It enables your doctor to develop a prognosis and treatment plan.

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, a biopsy is not required. Some risks are associated with liver biopsy, so a biopsy is performed only in situations in which it is deemed necessary to establish a diagnosis, or helpful for biomarker testing of the tumor, or to evaluate whether an underlying liver problem exists.

Blood tests are used to 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.

These tests, and others used for diagnosis and tumor molecular analysis, may be repeated later to monitor treatment effectiveness or determine a recurrence.

If a biopsy is performed, the results are examined by a pathologist, a doctor who has special training in identifying diseases by studying cells and tissues under a microscope. The pathologist then creates a pathology report, which includes results of tissue sample testing and biomarker testing, tumor molecular analysis or other tests.

Liver cancer is complex because patients often also have underlying liver disease. Several staging systems have been developed. Ask your doctor which is being used.

The two most commonly used staging systems for liver cancer are the Barcelona Clinic Liver Cancer (BCLC) Staging System — used primarily prior to operation and/or in patients that are not undergoing an operation — and the American Joint Committee on Cancer (AJCC)'s TNM Classification system — used primarily in patients after they have undergone an operation to remove the tumor for pathology examination.

BCLC STAGING SYSTEM

The BCLC classification system is used to plan treatment based on whether the cancer has spread within the liver or to other parts of the body, how well the liver is working, the general health and wellness of the patient, and the symptoms caused by the cancer (see Figure 1). 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.
3. The Child-Pugh score, a tool for evaluating how well the liver is working. This classification system uses five factors to determine treatment:
   - Albumin, a protein made by the liver.
   - Bilirubin, a part of bile, which is made in the liver.
   - Prothrombin time, a blood test to determine how quickly the blood clots. It is sometimes reported as International Normalized Ratio (INR).
   - Ascites, an accumulation of fluid in the abdomen or legs.
   - Encephalopathy, indicating whether liver disease is affecting brain function.

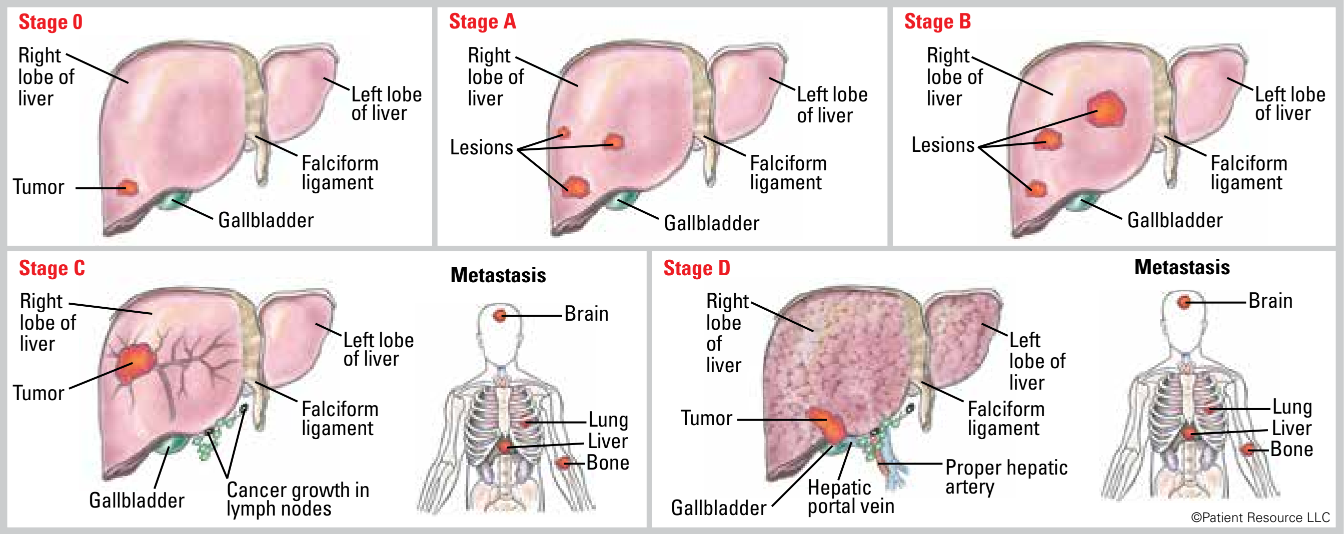
Each of these factors is scored into a point system, which tallies the number of points to assign one of three classes:

- Class A: a well-functioning liver
- Class B: liver function is moderately compromised
- Class C: liver function is severely compromised

Your doctor will combine the results from the three factors and classify the cancer

FIGURE 1

BCLC ILLUSTRATED STAGES OF LIVER CANCER



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into one of five BCLC stages from Stage 0 through Stage D. Stage 0 is very early-stage while Stage D is end-stage disease.

Doctors may also 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)

AJCC STAGING SYSTEM

The American Joint Committee on Cancer (AJCC) TNM classification and staging system is used to determine the size of the main tumor and whether the cancer has spread to lymph nodes and to distant parts of the body. This staging system is most commonly used in patients after they have undergone surgical removal of their tumor and the pathologist's report is available. A stage is assigned that ranges from I to IV (see Figure 2). The higher the number, the more severe the disease.

The TNM system 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. 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 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 combined to determine the overall stage of the cancer. The liver cancer is then given one of the following four stages:

- Stage I: A single tumor is confined to the liver.
- Stage II: A tumor larger than 2 cm and cancerous cells may have grown into nearby blood vessels.
- Stage III: Multiple tumors and/or growth into a major branch of the main blood vessels of the liver.
- Stage IV: The tumor(s) may be any size and has spread to regional lymph nodes and/or distant parts of the body. ■

➡ The BCLC and AJCC Liver Cancer staging tables are available to view online at: **PatientResource.com/Liver_Cancer_Staging_Systems**

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
INR-Prothrombin time	< (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

TABLE 2

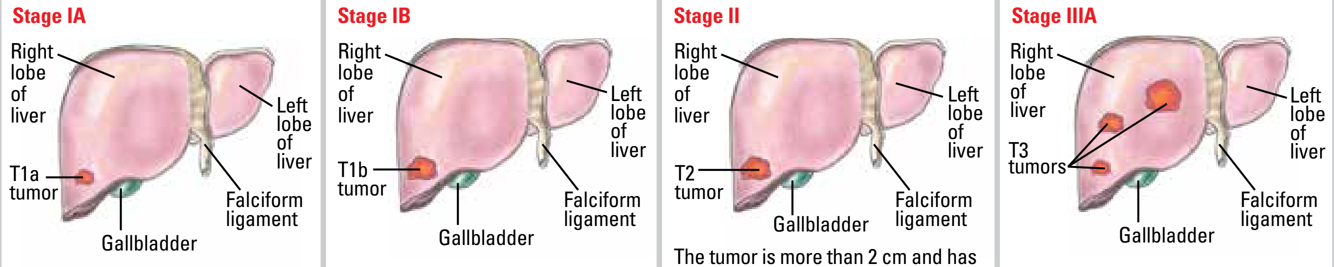
EASTERN COOPERATIVE ONCOLOGY GROUP (ECOG) PERFORMANCE STATUS

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.

FIGURE 2

AJCC ILLUSTRATED STAGES OF LIVER CANCER

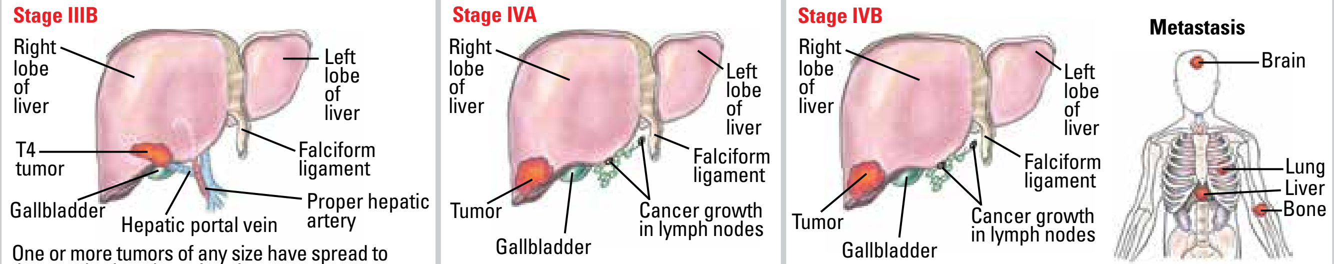


Stage IA The tumor is not more than 2 cm and is limited to the liver.

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

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



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

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

Explore every option with your health care team

Much discussion will happen before your treatment plan is decided, and you will be at the heart of it. Ask questions and give your input, then keep the lines of communication open. The more you know, the better equipped you will be to manage your hepatocellular carcinoma (HCC).

Your doctor will evaluate all of these:

- 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 metastasized (spread) outside the liver
- Whether your tumor has grown into blood vessels of the liver
- How well your liver is working
- Any healthy areas of your liver
- Any comorbidities (other serious health conditions)
- Your overall physical condition
- Expectations for your quality of life

Next, you will talk about your goals of treatment. Your prognosis (outlook) will help guide this discussion. Your goals may change as your condition changes. Be flexible and know your options if a change in treatment becomes necessary. Following are some goals to consider:

- 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 or “bridging to transplant”
- Slowing the cancer’s progression to extend life
- Using supportive 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 WAYS TO TREAT HCC

Following are some treatment options that may be available.

Monitoring (watchful waiting) may be used if a tumor appears to be slow-growing. With close monitoring and regularly scheduled blood and imaging tests, you may be able to avoid potential side effects until treatment becomes necessary. Stay on schedule with your appointments, because your doctors may recommend treatment if the pace of the cancer increases.

Clinical trials find new and better ways to treat and potentially cure HCC. Through these research studies, advances have recently been made for treating advanced HCC. Ask your doctor if a clinical trial should be part of your care plan now or at any time during your treatment (see *Clinical Trials*, page 8).

FIGURE 1

TRANSARTERIAL CHEMOEMBOLIZATION (TACE)

Transarterial chemoembolization (TACE) is a procedure used to treat liver cancer in which the blood supply to a tumor is blocked after anti-cancer drugs are given in blood vessels near the tumor. It also causes fewer side effects because very little of the drug reaches other parts of the body.

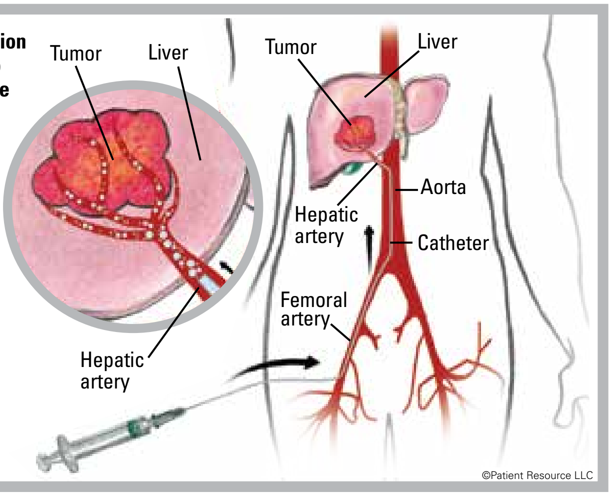


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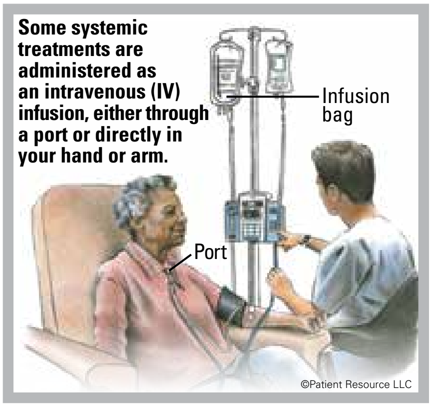
FIGURE 2

DRUG THERAPY

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



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Surgery, the primary curative method for treating HCC, is often complex and requires a high degree of training and skill. You are encouraged to have treatment at a cancer facility known for performing a high volume of liver surgical procedures, and one that has liver transplant as an option. Seeking a second or third surgical opinion is recommended.

Liver resection, also called a partial hepatectomy (HEH-puh-TEK-toh-mee), may be an option if you and your liver are healthy enough to undergo an operation; your liver is functioning well; the tumors are of appropriate size and location; the disease is early-stage; and blood vessels are not invaded by the cancer. In this surgery, a wedge, entire lobe or more of the liver that contains the tumor(s), along with a margin of healthy tissue, is removed. The remaining healthy part of the liver will continue to function as it regenerates (regrows), often to near normal size.

For complex operations, a liver resection may be performed as a traditional open resection. 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's 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 transmitted to a video screen in the operating room to guide the surgeon. Although one larger incision is typically made to remove the tumor from your abdomen, 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; however, only a very small percentage of people qualify for it. Candidates must meet strict criteria concerning the size, stage, location and number of tumors present. Other factors considered include 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 to ensure that the latest criteria for eligibility for transplant are integrated into your treatment considerations. The national and regional policies for these criteria are modified and updated relatively frequently. 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. Bridging therapy is designed to prevent the cancer from growing or spreading during the wait, which can sometimes be significant. Bridging treatments may include ablation, embolization, radiation therapy or systemic drug therapy.

During transplantation, 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.

Ablation destroys tumors with heat instead of removing them. It may be an option for small tumors and when surgery is not a good option. It is a better bridge to transplant than surgical resection.

Radiofrequency ablation (RFA) and ***microwave ablation (MWA)*** both involve use of imaging (typically CT scan) to guide a needle into the tumor. RFA uses radiofrequency electric current to generate heat, whereas MWA relies on electromagnetic microwaves at the tip of the probe to destroy the tumor. Both are equally effective, though MWA is used much more commonly now than RFA.

Cryoablation, also called cryosurgery or cryotherapy, is another form of ablation, but is used far less commonly than MWA and RFA. This technique involves delivery of an extremely cold gas through a hollow needle. This may also be referred to as thermal ablation.

Embolization therapies are generally not curative but can be very effective in extending life and improving quality of life.

Transarterial chemoembolization (TACE) combines chemotherapy with embolization. This minimally invasive procedure involves making a small incision in the groin and inserting a catheter, a thin, flexible tube that is guided with the help of imaging through the body to the artery that supplies blood to the liver (hepatic artery). Chemotherapy is administered into small hepatic arteries that are the main source of blood for most tumors developing in the liver. The arteries are blocked to allow the chemotherapy to remain 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 similar to TACE, but chemotherapy is not used. 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.

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 goal is to slow the growth of the tumors and reduce symptoms, although radioembolization may be used to shrink tumors to make surgery possible.

Drug therapy may be used to manage HCC.

Targeted therapy is designed to slow the cancer's progression by traveling through the bloodstream looking for specific proteins and tissue environments to block cancer cell signals. This, thereby, restricts the growth and spread of cancer.

An angiogenesis inhibitor is the type of targeted therapy most commonly used for HCC. Vascular endothelial growth factors (VEGFs) are commonly used.

Many targeted therapies are taken orally at home. They are systemic, which means the drugs travel throughout the body (see Figure 2). They may be used alone or in combination with immunotherapy.

DRUG THERAPIES FOR HCC

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

……

POSSIBLE COMBINATION THERAPIES

- ▸ atezolizumab and hyaluronidase (Tecentriq Hybreza-tqjs) with bevacizumab (Avastin)
- ▸ atezolizumab (Tecentriq) with bevacizumab (Avastin)
- ▸ ipilimumab (Yervoy) and nivolumab (Opdivo)
- ▸ tremelimumab (Imjudo) with durvalumab (Imfinzi)

As of 6/2/25

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 for HCC. They may 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 for HCC:

- 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.

Depending on the specific treatment, immunotherapy is given intravenously (IV) or by subcutaneous injection. It may be used alone or combined with another therapy.

Radiation therapy involves 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 to relieve pain and other cancer symptoms. Your doctor may talk with you about stereotactic body radiotherapy, image-guided radiation therapy and proton beam radiation therapy. ■

Scientific progress delivers hopeful options

Researchers work tirelessly to find new and improved ways to treat — and one day cure — liver cancer through clinical trials. Along with offering potentially life-saving treatments, participation in clinical trials as a patient offers valuable research for the entire medical community in the fight against cancer. Take this opportunity to learn about clinical trials so you can make an informed decision about including one in your treatment plan.

Most of the advances made in treating all types of cancer today were once therapies or procedures in the clinical trials process. For liver disease, those advances most recently include treating hepatocellular carcinoma (HCC) that has spread beyond the liver. Clinical trials that explore more effective treatments for intermediate-stage HCC are currently underway.

Like all cancer treatments, those used in clinical trials are accompanied by some risks; however, protecting a patient's safety is the number one priority. Every trial is designed with strict safety measures in place that were established and are enforced by the U.S. Food and Drug Administration. These strict guidelines are followed to ensure that all participants are protected throughout the clinical trial process and that they receive the most careful and safe medical care possible. This is done through several levels of safeguards and a set of rules called a protocol.

Talk with your medical team about the option of clinical trials as soon as possible after receiving your diagnosis. The various types of clinical trials can be part of your treatment plan as well as help you enjoy a better quality of life while managing the symptoms and side effects of liver cancer. Along with focusing on treatments, these research studies explore non-treatment strategies, such as disease prevention, patient screening, diagnostic tools and procedures, genetic risk factors and lifestyle/behavioral changes. Many trials also incorporate measures to improve your overall health and wellness.

If you find one that interests you, you will be provided with an Informed Consent form that outlines all components of that specific trial, including the purpose of the trial, the strategy being used, risks and expected benefits, potential side effects, your time commitment and more. You must closely review and sign the form before moving forward. If there is anything you don't understand, ask for an explanation. Also, it is important to know that even after signing the form and beginning the trial, you may leave it at any time and for any reason.

Doctors understand that people can experience the same disease differently because each patient is biologically and genetically unique. For that reason, clinical trials rely on the participation of a wide range of volunteers. It is vital that new medications are tested in clinical trials that reflect real-world populations to get a clear understanding of the drug's safety and efficacy. For everyone to get the most benefit from cancer research, volunteers of all ages, genders, locations, races and ethnicities, weights, sexual orientations and socioeconomic groups are needed. ■

10 Steps to Finding a Clinical Trial

While your medical team searches for clinical trials, you can look, too. Ask your friends and family members for their help. Using one or more of the clinical trial resources on this page, begin your search. Though each search site varies in how it is set up, they generally require the same information:

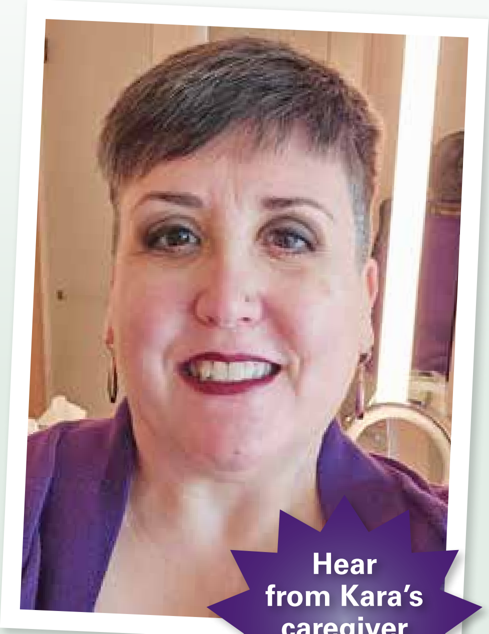
1. Gather your cancer diagnosis and treatment information.
2. Search by your specific liver cancer diagnosis.
3. Enter your age, preferred location, distance you will travel, etc., to narrow your search.
4. You will see a list of clinical trials. Review it and print the protocols for those you think may be a good fit.
5. Select a trial, and contact the clinical trial team listed for more information. Ask lots of questions, including those about side effects, how long the trial will last, financial responsibilities and more.
6. Discuss what you've learned about the trial with your doctor.
7. Undergo testing to see whether you are eligible. Every clinical trial has certain criteria you must meet to participate.
8. Talk it over with your loved ones. Thoroughly review and then sign the Informed Consent form.
9. Begin the clinical trial!
10. Continue to be an active participant in your care by keeping medical appointments, communicating with your medical team and doing your best to stay emotionally and physically healthy.

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/research/participate/clinical-trials-search
- **NCI Cancer Information Service:** 800-422-6237
- **WCG CenterWatch:** www.centerwatch.com, 888-838-5578

Look at life differently — and keep living

After multiple tests, doctors couldn't find any medical reason to explain 45 year-old Kara Klink's advanced liver cancer diagnosis. Rather than dwell on the cause, Kara chose to work closely with her medical team and make life changes that put her in control of her own destiny.



Hear from Kara's caregiver on page 15!

Severe abdominal pain that made it painful to breathe forced me to go to the emergency room one Friday night. I should have gone earlier, but as a dedicated oncology social worker, I wanted to wrap up things at work just in case it was something serious. It was. The ER doctor told me they had found metastatic cancer in my liver but weren't sure where it started. Colon cancer was a possibility, but we wouldn't know until I followed up with an oncologist.

I went home that night to my two cats that, coincidentally, I had inherited from a patient who had passed away from colon cancer.

That Monday, I was in my oncologist's office at 8 a.m. — not for work, like I should have been, but for his opinion. He was wonderful and calming. My CT in the ER had shown nothing in my abdomen, so he suggested we start with bloodwork and a biopsy.

Test results showed primary liver cancer with possible neuroendocrine tumor (NET) development. They found more than 20 tumors, the biggest of which was the size of a grapefruit. It was not a diagnosis I would have ever expected. I didn't have any comorbidities that would put me at risk for it.

While I waited for an appointment with a specialist, I had to move forward with treatment. I learned I was not a candidate for a liver transplant. The potential NET involvement required me to start chemotherapy as soon as possible. I was preparing to get my port when the medical team reviewed my bloodwork and told me the results were so dire that I needed to be admitted to a different hospital immediately.

There I began 44 hours of inpatient non-stop chemotherapy. I had all the side effects that you might imagine, but there was a silver lining to this otherwise awful stay. The specialist I was waiting to see was the doctor there. He and the pathologist did not feel there was NET involvement, and I was able to stop the chemotherapy and begin immunotherapy two days later.

When I shared my diagnosis with my family, friends and co-workers, I emphasized the severity of it. I wanted them to understand that my care was palliative, not curative. Mostly, I didn't want them to be shocked if something happened. I also think it was a way of helping me avoid processing it.

I'd also made a list of people I wanted to reach out to, including my high school boyfriend, Jeff. He had been "the one" but I ended it. I wanted to tell him that I was sorry. It turned out to be one of the best decisions I made.

I trusted my doctors to manage my treatment, which allowed me to look at the whole cancer situation in a new light. At first, I wondered how my body could do this to me. I found a lot of comfort in reading about Eastern views about the liver holding pent up anger. That spoke to me, and it made me realize that my body wasn't the enemy. My liver was telling me I could keep going as I was and I wouldn't be here very long. Or, I could reevaluate how to make my life better, and I may be here longer. That meant I had to stop working two jobs, not eating and sleeping properly, and running on adrenaline and stress. And, I could start thinking of myself as Kara, a person who has cancer. Not "liver cancer Kara." It's a totally different way to look at things.

Finding support was life-changing. I have amazing friends and family, but there are things I don't want to talk to them about because I don't want to upset them. About a year after diagnosis, I found a *Patient Resource Liver Cancer Guide* when I was going for a second opinion. It was like the heavens opened up. I discovered Blue Faery, and I knew I'd finally found my people! I volunteer and share my story wherever I can. I was put on this earth to help people, and now I can again.

The immunotherapy is doing what it is supposed to do. The only side effects are fatigue and joint pain. I understand that my body can't do what it did before, but I try to give myself a little grace. Palliative care is essential. It helps with pain and with validating my emotions.

After two years on continuous treatment, I now get the same treatment but with breaks. It's a better quality of life for me. I'm thrilled to report my labs are all normal, and my scans have shown incredible shrinkage.

I was so happy when Jeff and I reconnected, but I never imagined we'd get back together. He surprised me with an engagement ring on the anniversary of my diagnosis. It's a day I celebrate because it has led me to where I am today, and now it is even more special. ■

Ensure your well-being through preparing for side effects

Facing a liver cancer diagnosis may feel overwhelming emotionally and physically. But you will not face it alone. Preventing, minimizing and managing the side effects of any underlying conditions, the cancer and its treatment are a primary focus of your multidisciplinary health care team. They will work together to make you more comfortable and enhance your quality of life. Knowing the side effects that may occur – and setting expectations for how to manage them if they do – will help you feel more prepared for treatment.

Today, people with cancer have access to services that are designed to help improve their overall well-being before, during and after treatment. These services are known as supportive care and include assistance with nutrition, fitness, mental health and physical/occupational therapy. They also address the practical, spiritual, financial and family-related challenges associated with cancer. Because your diagnosis also affects your loved ones, your family members, caregivers and others close to you can access this support.

As you discuss treatment options with your doctor, ask about the potential side effects of each. Keep in mind that how you respond to those side effects will depend on many factors, including your specific diagnosis, health history, age and other characteristics. People often respond differently to the same treatments, so you cannot expect your experience to be like that of anyone else.

Lean on your health care team to help you navigate your journey. Their help will be invaluable throughout your experience, but they can only be effective if you communicate openly and honestly with them. The sooner your team knows about any concerns you have, the more quickly they can be addressed. Keeping track of your side effects helps you provide the most complete information. Ask whether telehealth appointments or an online portal are available for reporting symptoms or complications between follow-up visits.

COMMON PHYSICAL SIDE EFFECTS

Some physical side effects can be disruptive while others are merely an annoyance (see Table 1). Ask your doctor how to recognize symptoms, when they might occur and ways you can help manage them. 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.

Stay alert to the possibility of late effects. These are side effects that develop weeks, months or even years after treatment ends. They are typically hard to predict so knowing what to do if one occurs is key.

POTENTIALLY SEVERE SIDE EFFECTS

Serious side effects are usually uncommon, but they can occur with some treatments. Ask your doctor whether any therapies in your treatment plan could cause them, and find out how to identify the symptoms. Report them immediately if they occur. Prompt medical attention can be lifesaving.

- **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

Both patients and caregivers need emotional support

A cancer diagnosis can bring up a range of emotions, whether you are the patient or the caregiver.

Both parties will immediately face the fear of this new reality. A person diagnosed with liver cancer will experience the direct stress of treatment and the caretaker will often take on added responsibilities for a loved one. Keep in mind that flexibility, patience and compassion will be key for everyone.

In fact, research supports the idea that improving a patient's emotional well-being can help them better cope with cancer-related issues. The same is true for caregivers who can face burnout and exhaustion both physically and emotionally. Monitor each other for mental and emotional health and watching for signs of distress.

Common emotions of both patients and caregivers include fear, stress, anxiety, sadness, depression, anger, loneliness and guilt. These feelings may come and go and sometimes be much worse than others. Give yourself permission to move through these emotions and know that all of them are normal.

Following are some ideas for maintaining and improving emotional health for people who are diagnosed with liver cancer and their loved ones and caregivers:

- Express your feelings. Don't keep them bottled up.
- Don't try to be upbeat when you are not. It is okay to have bad days.
- Find ways to relax, such as meditation, yoga, walking, guided imagery, reading, journaling and spending time in nature.
- Be as active as possible. Even a 10-minute walk can do wonders for your mental well-being.
- Find new hobbies and activities you enjoy.
- Think about what you can control to help bring your mind some peace.
- Breathe deeply to calm anxiety or try other relaxation methods.
- Call a friend or family member.

Consider reaching out to support groups. Many are available online or in person for anyone affected by liver cancer, and they have sessions for caregivers and patients to attend independently. A caregiver may be afraid to share their feelings of fear with their loved one facing cancer. An opportunity to open up with other caregivers can help manage these emotions to allow for easier caregiving and remind them to care for themself as well.

People facing liver cancer can learn a lot by connecting directly with others who are in the same situation and receiving similar treatments. Sharing experiences and feelings with others living through liver cancer can provide hope and encouragement while also validating their emotions.

Both patients and caregivers will need to practice self-care and be empathetic to each other. If it feels that the strategies you are using are not working, don't be afraid to ask your health care team to provide a referral for professional help.

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 experienced by an otherwise healthy person. Contact your doctor immediately if fatigue prevents you from carrying out your daily activities.
- **Hepatic encephalopathy (HE)** occurs when the liver is unable to filter toxins in the blood sufficiently. The buildup of these toxins affects the brain and its ability to function normally. Ask your doctor about symptoms to watch for and when to go to the emergency room. These signs are often noticed by caregivers first.
- **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; 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. Common symptoms of irAEs may include fever, joint aches, skin rash, cough and diarrhea. Discuss with your doctor how to recognize signs of irAEs.
- **Infusion-related reactions** most frequently occur with treatments given intravenously (IV) through a vein in the arm and usually happen 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. ■

TABLE 1

SOME COMMON PHYSICAL SIDE EFFECTS*

Side Effects	Symptoms
Abdominal pain	Cramping and dull aches in the abdominal area
Anemia	Abnormally low red blood cell count
Ascites	Abdominal swelling from fluid accumulation in the abdomen
Bleeding problems	Bleeding or 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 and 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 a healthy person experiences; may also be caused by anemia, a lower-than-normal red blood cell count
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and/or body, which is a side effect of some chemotherapy drugs
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
Hepatic encephalopathy (HE)	Cloudiness in mental function or somnolence (sleepiness) that occurs if the liver is unable to adequately remove toxins from the bloodstream
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
Neutropenia	Abnormally low number of immune cells (white cells), which is a side effect of some chemotherapy drugs
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 may change
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.*

Develop a personal nutrition strategy

Liver cancer patients generally have high caloric requirements, yet treatment for liver cancer, as well as the cancer itself, can create many nutrition-related challenges. Nutrition plays an important role in helping you manage your diagnosis. It will help you stay stronger, both physically and mentally. Think of it as a type of treatment that you control — and being in control at this time can be a very satisfying feeling.

When the liver is damaged from cancer or another disease, your metabolism is often affected. As a result, the way your body absorbs food may change, which can affect your weight, appetite and the vitamins your body can absorb. When you cannot consume all the protein and vitamins your body needs, you may become malnourished. Losing too much weight can lower your energy levels and decrease your body's ability to fight infection and endure treatment.

MAKE A PLAN

You are encouraged to talk with your care team soon after diagnosis, or at any time, about your nutritional needs. Your doctor may perform an assessment to establish your baseline nutritional information. Using this information, a nutritionist on your care team can help you create a personal nutrition strategy that is tailored to your type of liver disease, as well as your likes and dislikes. The goal is to help you adopt comfortable, consistent eating habits that prevent malnutrition, dehydration and weight or muscle loss.

Developing a solid relationship with your nutritionist is important. Together, you can create the best plan for you. After all, you eat every day — and you should enjoy it! Get the ball rolling by asking a few questions:

- What is good for my liver?
- What can I eat that won't make me sick (especially if I'm feeling nauseated from treatment)?
- How can I keep weight on (if treatment is causing weight loss)?
- If I am obese, have a fatty liver or have Type 2 diabetes, what can I eat that is nutritious and won't make my other conditions worse?
- Does my specific set of conditions require me to limit my intake of salt?
- What is the best way to reach you when I have more questions (phone, text, portal)?
- Can you recommend support groups or other resources for me?

BEFORE, DURING AND AFTER TREATMENT

Your nutrition strategy will be unique to you and may need to be adjusted as you go along, but don't worry. That is expected. Following are some general recommendations, but always check with your doctor or nutritionist.

Before treatment. If you are scheduled for chemotherapy, it is often recommended you follow a low fat, high carbohydrate, high protein diet. Plan for appetite loss, which is a common side effect during liver cancer treatment. It puts you at risk of weight loss and is commonly caused by nausea. If you are scheduled for liver resection, some surgeons will recommend that you follow a low carbohydrate, low calorie diet only immediately before surgery, as this reduces liver glycogen stores which can reduce bleeding during surgery on the liver.

During treatment. If you are currently undergoing chemotherapy, eat a low-fat, high carb diet with small quantities of good quality protein. It may help to eat extra carbohydrates if you are having radiation therapy. Consider not eating your favorite foods a day before treatment in the event you develop a side effect like nausea which could cause you to develop a negative association with them.

If symptoms are severe enough, they may prevent you from finishing treatment. Nutritional supplementation may be needed. Rarely, doctors may prescribe parenteral nutrition (intravenous feeding) if eating is too difficult, your digestive tract is not working or there is a blockage that is leading to significant malnutrition.

It is also important to avoid dehydration because it can lead to kidney problems. Cancer treatment and its side effects can dehydrate the body, making it very important to drink plenty of water or fluids throughout the day. Be sure to ask your doctor how much fluid you will need each day.

Try to get some exercise each day. Exercise improves quality of life and general wellness. Recommendations will vary from person to person. Just stay active in some way. If you are frail or malnourished, your doctor may suggest balance training to strengthen postural muscles and improve your range of motion.

After treatment. Eat a high protein diet and, with your doctor's approval, consider antioxidant supplements and taking vitamins E and C. After radiation therapy, avoid simple sugars and lactose to avoid intestinal discomfort. Post-drug therapy, have small and frequent meals that are easy to digest. ■

» Healthy Habits

Keep in mind that these changes can be made gradually. Everything doesn't have to happen at once:

- **Consume foods and beverages high in protein. Protein helps the body repair cells and tissues and helps your immune system recover from illness.**
- **Eat a variety of fruits, vegetables, whole grains and beans. Research shows that plant-based diets decrease risk of some specific diseases and cancers.**
- **Include healthy fats like avocados, nuts/nut butters and seeds in your diet.**
- **Experiment with eating multiple small meals throughout the day rather than three big meals. This may help with nausea.**
- **Identify when your appetite is the best and plan to have your biggest meal of the day at that time.**
- **When possible, avoid consuming added sugars, alcohol, salt and saturated/trans fats. These foods provide little nutritional benefit.**
- **Your health care team usually prefers that you get most of your nutrients from food, so talk to them before taking any vitamins or supplements.**

Get to know your case manager

Managing your cancer diagnosis and treatment is your top priority right now, as it should be. However, many practical responsibilities that go along with a cancer diagnosis must be addressed, even though they may not feel important in the whole scheme of things. Your case manager can help you navigate these responsibilities, reducing or eliminating your stress and allowing you to focus on healing.

WHAT IS CASE MANAGEMENT?

Case management is a typically free resource designed to help manage the practical issues related to a serious illness such as liver cancer. These issues are considered barriers to care because they can prevent you from receiving the best care and services available.

A case manager will be your link to overcoming these barriers. Your case manager may be a social worker, financial counselor, nurse or some combination of these areas of expertise. Acting as your personal advocate, they will draw on their professional experiences as they collaborate with health care professionals and non-medical personnel.

Alan Balch, PhD, Chief Executive Officer at Patient Advocate Foundation (PAF), understands the value of helping patients find solutions to the problems they face during treatment.

"Our case management program is a process of directly assisting patients and their caregivers in finding and securing appropriate resources or dealing with specific barriers. In our experience, the areas in which patients need help most are transportation, paperwork and finding financial assistance to cover various costs."

Financial concerns are understandably some of the most common with cancer care. They make an already stressful situation even more difficult. That added worry can affect you emotionally and physically, which isn't good for your health.

Your case manager can help you carefully review your insurance policy so you know the rules and procedures to follow and what treatments are covered, including the items covered by Medicare Parts A, B, C and D. This is crucial information in regard to treatment options, and you are encouraged not to make these important decisions until you've looked into the financial resources that are available. This applies to you even if you are uninsured or underinsured.

Fran Castellow, MSEd, Patient Advocate Foundation (PAF), believes no patient should have to struggle with financial obstacles alone.

"Our expert case managers work alongside the patient or caregiver to identify solutions to problems surrounding insurance, medical debt and many other challenges, as well as helping them better afford their out-of-pocket costs."

You may also have medical questions that do not require the attention of a health care professional. While your health care team focuses on your treatment and side effect management, your case manager can assist with practical needs. Those may range from screening and assessment to care coordination, discharge planning and transportation.

Your case manager can even help with the indispensable services surrounding end-of-life needs. If you choose to be at home at this time, a case manager may be available to arrange for door-to-door transportation from the medical facility to home, and ensure a hospice company, necessary equipment and a nurse are on site before you arrive. The goal is to help you feel secure and comfortable, surrounded by people who care, in the last moments of life.

NEXT STEPS

Not all hospitals or treatment centers have case management programs, but they may have someone who takes on that role. Ask about this resource soon after you receive your diagnosis. If your care team does not have a case manager on staff, request a referral. You deserve all the resources you can get.

Once you connect with a case manager, keep the lines of communication open. Share contact information with each other and decide on the best way to keep in touch, such as through texting, phone calls, emails or a health care portal. Introduce your caregiver or loved ones to broaden that circle of support.

Realize that case management comes in many different forms. Your case manager can help you with a very specific and short-term need. Or, you may have a long-term need, and you can begin working with a case manager right after diagnosis and continue to benefit throughout treatment.

Lastly, how you choose to use this valuable resource is based on your needs, but you can take comfort in simply knowing it is available. ■

Make a plan for moving forward into a new way of living

People define survivorship differently. Some people consider themselves survivors upon receiving a cancer diagnosis. Others take on the role once they have moved past active treatment. Still others prefer no label at all. Either way, survivorship will bring about change in many areas of your life.

According to the Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, the number of cancer survivors is increasing. Advances in early detection, innovations in treatment options and improvements in side effect management can be credited with this promising news.

YOUR SURVIVORSHIP PLAN

Managing your health in this stage of your journey will be easier when you know how to proceed. You will work closely with your doctor to develop a survivorship plan that includes pertinent information about your care, such as 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.

You and your doctor will then customize your plan around your expectations for the future. Your plan will likely include the following:

- A schedule for follow-up tests and exams
- The symptoms that should prompt you to call the doctor
- Reminders for appointments with other health care providers
- Referral(s) for cancer rehabilitation, such as physical or occupational therapy
- Information about your risk of a recurrence, screenings for second cancer, long-term treatment-related side effects and late effects
- Goals for a healthier lifestyle

PREPARE FOR FOLLOW-UP CARE

Follow-up care is key in a survivorship plan because for many people, all cancer-related effects don't disappear when treatment ends. And recovery from the physical, emotional and mental aspects of cancer may take more time than many survivors and their families expect. Before you resume care with your primary care physician, ask your oncologist to set up a long-term follow-up care plan.

Once you have the plan, be sure to use it. Making and keeping follow-up appointments allows your health care team to keep a close eye on your health, manage any side effects, help you feel your best and check for cancer spread or recurrence. These appointments also give you the opportunity to ask questions, share your concerns and get one-on-one assistance from your doctor, oncologist, rehabilitation therapist and others.

For some people, the liver cancer may never go away completely, or it might come back in another part of the body. This can be difficult and stressful. Follow-up visits are also important for keeping in touch with a social worker, mental health counselor, nutritionist and palliative care clinicians.

PRIORITIZE MAKING SMART CHOICES

Focusing on your long-term health in the following ways may help you better cope with your cancer and treatment and also improve your quality of life.

Lead a smart lifestyle that includes both a nutritious diet and regular exercise. A nutritionist can help you create a strategy that includes colorful fruits and vegetables and limits foods thought to increase cancer risk. Moving your body in general can lead to better physical functioning and an overall better quality of life. Even 10 minutes of walking each day can increase your energy level, improve your mood and relieve fatigue. These changes may help improve other conditions you may have, such as obesity, heart disease and diabetes, which have been linked to cancer.

Stay on schedule with medications. Take the right dose as prescribed by your doctor at the right time, every time. Use the many tools available, such as alarms, smartphone apps and notes, to remind you to stay on schedule. If you experience side effects that make you want to stop your medication, talk with your doctor or pharmacist right away. Cutting back on doses reduces the effectiveness of your cancer drugs. Never make a change without the direction of your medical team.

Listen to your body and track any changes or symptoms you experience, even if they seem small or unimportant. Don't, however, do an inventory of your body every day. Keep your medical team informed of anything that is concerning.

Be diligent about scheduling and completing regular follow-up appointments and tests such as exams, blood work, imaging tests and biomarker tests.

Address how you feel mentally and emotionally, including discussing 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. Always talk with your medical team or pharmacist before beginning these.

SURVIVORSHIP SUPPORT

As a survivor, you will have access to many types of support. These may include your cancer center, survivorship clinics, support groups, cancer advocacy organizations and other local or area resources. Survivor phone buddies and peer-to-peer matching, and online survivorship support groups and communities are more options.

If your doctor doesn't give you a survivorship plan, download and print a copy 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 in what you can before meeting with your doctor. ■

Caring for a loved one with a chronic illness

Taking on the role of caregiver for a person who has HCC requires a great deal of strength, both physically and emotionally, and especially if the disease becomes advanced. Although it may be difficult, remember that caring for your loved one will make a significant difference in their quality of life. Following are some of the ways you can help.

Get the "OK" to receive medical information. Without this, you will not be authorized to communicate with the health care team, access medical information, renew prescriptions and more. Make it a priority to ask the health care team about how to make this happen.

Meet the care team. Introduce yourself and ask for contact information for members you might need to reach out to, such as the doctor, nurse navigator and nutritionist. Find out how they prefer to be contacted (phone call, email, text or health care portal).

Go to medical appointments. The amount of information a patient is expected to absorb may be overwhelming. Hearing information from the care team firsthand will relieve the responsibility from your loved one, and it will help you provide better care, whether it involves managing side effects, learning test results or preparing for a procedure. Ask questions, take notes or record the appointment on your phone, and provide emotional support.

Give medication safely. Taking the correct medication at the right time and in the right amount is essential for treatment to work as it is intended. To avoid giving too much or not enough, it helps to write it down. Download a medication tracking form at PatientResource.com/Medication_Journal

Watch for and manage side effects. Ask the care team about the side effects and symptoms to watch for. Track when they happen, how often and if anything makes them better. Providing as many details as you can to the care team will help them better offer relief. Ask about symptoms that may require urgent assistance so you can be prepared. Download a tracking form at PatientResource.com/Tracker.

Set up support systems. Help your loved one find support from other people managing HCC, then look for support for yourself. You each need your own safe space for asking questions, sharing your feelings, etc. Use the resources in this guide to find local and online cancer support groups. Many have peer-to-peer counseling and groups for caregivers.

Champion a healthy lifestyle. Shop for and make healthy meals for your loved one. The nutritionist on the care team is an excellent resource. Encourage exercising, getting enough sleep and making and keeping all preventive medical appointments. It is easier to make these changes with a partner, and taking this good advice will benefit you, too.

Practice self-care. You will be a more effective caregiver if you take care of yourself physically and emotionally. Though you may not have as much free time as you did before, carve out blocks for leisure activities. Read a book, work out, meet a friend for coffee, whatever brings you joy. It is essential for your well-being. ■

Caregiver Perspective | JEFF CAPE

How I came to be Kara's caregiver requires some background. We are high school sweethearts who reconnected shortly after Kara received her liver cancer diagnosis. Knowing her prognosis was grim, she reached out. It didn't take long for our friendship to turn into love. Knowing full well how fragile her health was, I proposed. I came into this relationship with my eyes wide open.

Read Kara's story on page 9!

My career includes travel, but it works out well because Kara doesn't need my help with personal care. She does, however, get extremely fatigued, so most of my caregiving responsibilities are the day-to-day ones, such as shopping, cooking and cleaning. According to her, though, how I help her best is through emotional and spiritual support.

We both feel strongly about the connection between mind, body and spirit, and we are big believers in making sure our energy is going to the right place. Unfortunately, even though Kara is a natural caregiver and has always focused on taking care of others, she realized she wasn't getting that back from some of her relationships. That was mentally and physically draining. So, we took a look at the people around us and identified the relationships that weren't two-way. We set boundaries for some and decided others weren't worth the effort. It was healing and allowed her to put her energy into positive places.

Communication is also a big component of our relationship. We talk about everything, from how she is feeling to how we envision our end-of-life situations. These topics don't freak us out because we're practical, and we know death is a natural part of life.

Something I don't do, and would encourage other caregivers to avoid, is mourn the person while they are still here. Any of us could pass away tomorrow. All that matters is what we do today.

No matter what our future holds or what my responsibilities as her caregiver become, it will still be better than anything I've ever had in my life. Our job is to find joy, and what Kara and I have is pure joy. ■

Support and financial resources available for you

CANCER EDUCATION

American Cancer Society	www.cancer.org, 800-227-2345
CANCER101	www.cancer101.org, 646-638-2202
Cancer*Care*	www.cancercare.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
OncoLink	www.oncolink.org
Patient Resource	www.patientresource.com, 800-497-7530

CAREGIVERS & SUPPORT

BeholdBeGold	www.beholdbegold.org
Cactus Cancer Society	www.cactuscancer.org
CanCare	www.cancare.org, 713-461-0028
CANCER101	www.cancer101.org, 646-638-2202
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 Support Community	www.cancersupportcommunity.org, 888-793-9355
Cancer Support Community Helpline	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
Livestrong Foundation	www.livestrong.org, 855-220-7777
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

CLINICAL TRIALS

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, 877-633-4376
ClinicalTrials.gov	www.clinicaltrials.gov
Lazarex Cancer Foundation	www.lazarex.org, 877-866-9523, 925-820-4517
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

Accessia Health	www.accessiahealth.org, 800-366-7741
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

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

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline	866-276-7443

NUTRITION

American Cancer Society	www.cancer.org, 800-227-2345
Cancer*Care*	www.cancercare.org, 800-813-4673
Cancer Support Community	www.cancersupportcommunity.org, 888-793-9355
LLS Nutrition Education Services Center	www.llsnutrition.org, 877-467-1936
OncoLink	www.oncolink.org

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.medicineassistancetool.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

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

AstraZeneca Access 360	myaccess360.com/patient, 844-275-2360
AstraZeneca Patient Savings Programs for Specialty Products	astrazenecaspecialtysavings.com, 800-236-9933
AstraZeneca Prescription Savings Program (AZ&ME)	azandmeapp.com, 800-292-6363
Avastin Access Solutions	www.avastin.com/patient/financial-resources.html, 888-249-4918
Bayer US Patient Assistance Foundation	www.patientassistance.bayer.us/en/ 866-228-7723
Bristol-Myers Squibb Access Support	bmsaccesssupport.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation	bmspaf.org, 800-736-0003
Cabometyx EASE	www.cabometyx.com/cost-financial-support, 844-900-3273
Exelixis Access Services (EASE)	https://www.ease.us/ 844-900-3273
Genentech Access Solutions	genentech-access.com/patient, 877-436-3683
Genentech Oncology Co-pay Assistance Program	copayassistancenow.com, 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	855-398-7832, press 2
Keytruda Merck Access Program	merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Lenvima Eisai Reimbursement Resource	eisaireimbursement.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, 800-545-5979
Merck Helps	merckhelps.com/KEYTRUDA, 855-257-3932
Opdivo with You support program	www.opdivo.com/opdivo-with-you-sign-up, 855-673-4861
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
Together with GSK Oncology	togetherwithgskoncology.com/patient-information/jemperli/, 844-447-5662
Vitrakvi Access Services by Bayer	www.vitrakvi-us.com/patient-assistance-program, 800-288-8374
Yervoy BMS Access Support	bmsaccesssupport.com, 800-861-0048

For more resources, go to PatientResource.com

I'D RATHER BE DEAD THAN DEAF

A YOUNG WOMAN'S JOURNEY WITH LIVER CANCER

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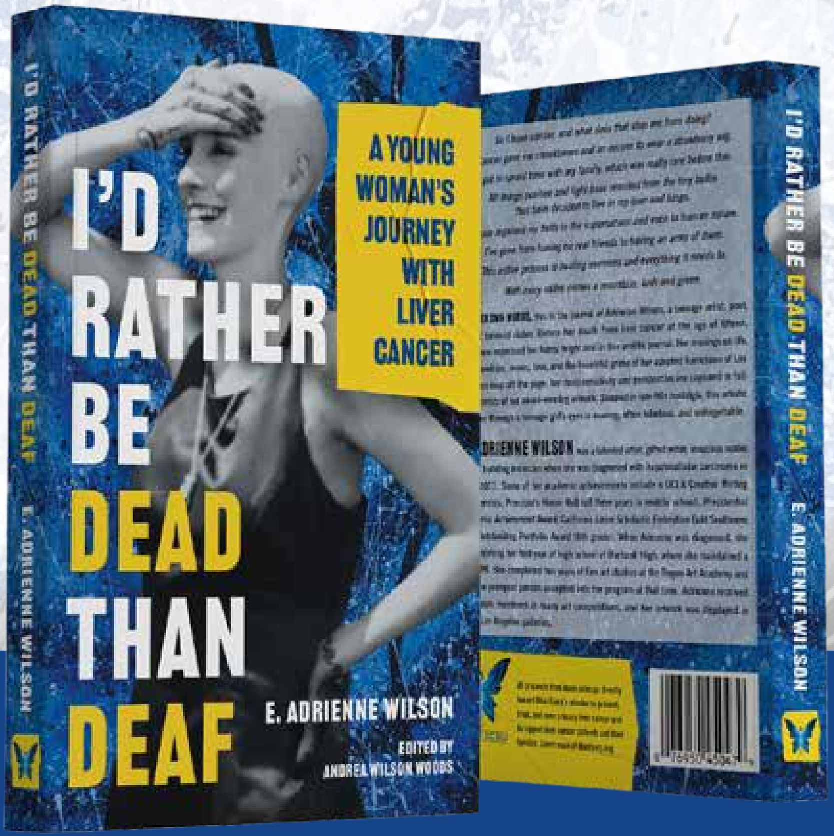

ABOUT THE BOOK

In her own words, this is the journal of Adrienne Wilson, a teenage artist, poet, and beloved sister. Before her death from liver cancer at the age of fifteen, Adrienne expressed her funny, bright soul in this prolific journal. Her musings on life, relationships, music, love, and the beautiful grime of her adopted hometown of Los Angeles leap off the page; her deep sensitivity and perspective are captured in full-color prints of her award-winning artwork. Steeped in late-90s nostalgia, this artistic journey through a teenage girl's eyes is moving, often hilarious, and unforgettable.

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