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LIVER CANCER

A Treatment Guide for Patients and their Families



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OVERVIEW

“Disease within a disease” affects a most essential organ

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. You will likely see and hear many new words that contain these elements. There are two main types of primary liver cancer: one is called hepatocellular carcinoma or HCC, which begins in liver tissue, and the other is called cholangiocarcinoma, which begins in cells that line the bile ducts. Although other types of cancer can metastasize (spread) to the liver, a condition known as secondary liver cancer, this guide focuses on adult primary liver cancer.

HCC generally develops in the presence of underlying chronic liver disease. For this reason, it is often called a disease within a disease. The underlying cause and the cancer must be addressed, which makes HCC challenging both to diagnose and treat.

UNDERSTANDING THE LIVER

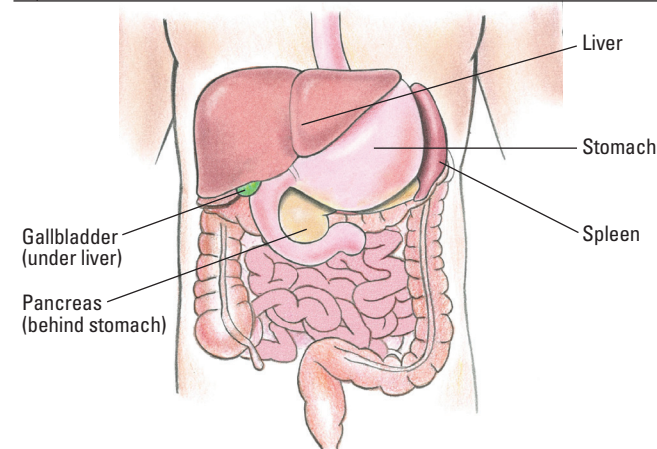
Just as you cannot survive without your heart, you cannot survive without your liver. It plays a vital role in more than 500 functions in your body. These include cleaning your blood by filtering out toxins and waste, secreting bile to the intestines to aid with digestion and making clotting factors to help stop bleeding.

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

HOW LIVER CANCER DEVELOPS

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

FIGURE 1
ANATOMY OF THE ABDOMEN



©Patient Resource LLC

HCC begins in the hepatocellular cells, which are the main type of cells in the liver. 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 the bone.

Most patients do not have any symptoms. However, symptoms may include 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 or 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.

The most common underlying disorder is cirrhosis, which is scarring of the liver. This long-lasting, progressive disease causes inflammation and irreversible damage over time, as scar tissue slowly replaces healthy liver cells as the organ gradually loses function.

Most risk factors for HCC can also cause cirrhosis:

- Viral hepatitis B and C (HBV and HCV), which are carried and spread through contact with blood and other bodily fluids.
- Heavy use of alcohol.
- Environmental factors, such as certain chemicals or aflatoxin (a toxin made by a mold).
- Nonalcoholic fatty liver disease (NAFLD) and its most severe form, nonalcoholic steatohepatitis (NASH), which have been linked with obesity.

In some cases, however, no risk factors are found, and it is not known what causes the liver to become compromised and vulnerable to HCC.

DISEASE STIGMA

Because many of these underlying conditions can be related to lifestyle choices, liver cancer is associated with “disease stigma.” This occurs when people make negative assumptions about or assign blame to individuals with certain diagnoses, such as liver disease, lung cancer, HIV/AIDS, adult diabetes and other conditions. Some people diagnosed with HCC feel such embarrassment and shame that they withdraw, avoiding friends and family. They may even avoid medical appointments, which, in turn, can affect their outcome. Loved ones and caregivers can also feel this burden.



“We work hard every day to eliminate the stigma surrounding liver cancer. No one deserves this or any other cancer diagnosis.”

Andrea J. Wilson, president & founder,
Blue Faery: The Adrienne Wilson Liver Cancer Association

It is extremely important to understand that nothing you have done makes you deserve a cancer diagnosis, and you do not have to face HCC alone. Supportive care, also called palliative care, includes a variety of resources available at most cancer centers and hospitals and through advocacy groups (see *Supportive Care*, page 11).

In addition to helping you manage the physical aspects of an HCC diagnosis and treatment, 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.

NEXT STEPS

Both the cancer and the underlying condition must be addressed during treatment, along with any other serious health conditions, such as heart disease or lung problems. These factors, coupled with the relative rarity of HCC in the U.S., make it crucial to seek treatment at a cancer center or hospital with significant experience treating liver cancer. A multidisciplinary team of specialists is required to accurately diagnose and stage the cancer, plan effective treatment and coordinate supportive care to help manage side effects.

Ask about clinical trials taking place in the U.S. and in other parts of the world you may qualify for. More people are considering clinical trials earlier in their treatment plan because they become too unhealthy later in the course of their disease to be eligible for a clinical trial. In some situations, it may offer the best chance for a positive outcome, so talk with your doctor about this treatment option (see *Clinical Trials*, page 10).

Do not hesitate to get a second or even third opinion before making any treatment-related decisions (see *Treatment Options*, page 8). Your oncologists should be both pleased to

and capable of helping you arrange for a second opinion. Many patients mistakenly believe that their oncologist will think poorly of them if they ask for a second opinion. But this is part of a physician’s obligation to you, and a request that physicians commonly receive.

Learning everything you can about your diagnosis is empowering. Your patient/nurse navigator, oncology nurse, other members of your health care team and liver cancer survivors may offer valuable insight. You can also take advantage of the reliable resources in the back of this guide (see *Assistance*, page 15).

The more you know about liver cancer, the better prepared you will be to make treatment decisions with your doctors. Actively participating in the direction of your care will offer you a much-needed level of control as you plan the way forward. ■

[KEY TAKEAWAYS]

- ▶ **Your liver is essential to your body and plays a vital role in more than 500 functions.**
- ▶ **Seek a specialist to treat HCC.**
- ▶ **Explore the possibility of a clinical trial before beginning treatment.**
- ▶ **Access supportive care resources for you and your loved ones as soon as possible.**

ADDITIONAL RESOURCES

- ▶ **American Cancer Society:**
www.cancer.org
If You Have Liver Cancer
Liver Cancer
- ▶ **American Society of Clinical Oncology:**
www.cancer.net
Liver Cancer: Diagnosis
- ▶ **Blue Faery: The Adrienne Wilson Liver Cancer Association:**
www.bluefaery.org
Hepatocellular Carcinoma

Several key factors will guide your path forward

Staging is how physicians determine the extent of cancer, where it is located and whether it has spread to nearby organs or tissues or to other parts of the body. Your doctor will consider the results of your physical exam, diagnostic tests and pathology report to stage your cancer and develop your treatment plan. Staging can also assist with determining a prognosis (outlook).

The most common staging system used for hepatocellular carcinoma is the Barcelona Clinic Liver Cancer (BCLC) system. This system is based on three main factors:

1. **Tumor characteristics**, including the size of the tumor(s), how many tumors are present and if 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.
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 part of the International Normalized Ratio (INR).
 - **Ascites** is an accumulation of fluid in the abdomen.
 - **Encephalopathy** indicates if liver disease is affecting brain function.

Each of these measures 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

The results of the three factors, which include the tumor characteristics, the ECOG Performance Status and the Child-Pugh score, are then combined to determine an overall stage.

In general, using the BCLC system, liver cancer may be classified into one of the following five stages:

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 diag-

nosis. 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). Liver cancer may be called localized resectable (confined

to the liver and able to be surgically removed), localized unresectable (confined to the liver but cannot be surgically removed), or advanced (has spread beyond the liver and likely can't be treated with surgery).

The BCLC system staging table, Child-Pugh scoring system and ECOG Performance Status tables, along with liver cancer staging illustrations, can be found on page 4.

Another staging system that may be used is the TNM system developed by the American Joint Committee on Cancer (AJCC). See page 5 for AJCC system staging content and illustrations.

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.

See
Staging
tables and
illustrations
on pages
4 & 5

KEY TAKEAWAYS

- ▶ **Staging is how your doctor determines if cancer is confined to the liver or if it has spread to other parts of the body.**
- ▶ **Staging helps your doctor determine the best treatment plan for you.**
- ▶ **A second opinion from an experienced liver specialist could offer valuable additional information.**
- ▶ **Ask your doctor to explain anything you don't understand. Feeling well-informed will help you make important decisions going forward.**

ADDITIONAL RESOURCES

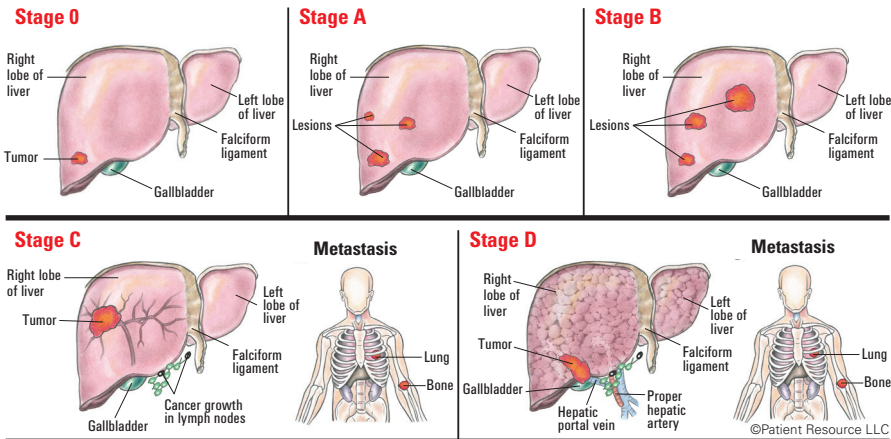
- ▶ **American Cancer Society:**
www.cancer.org
Liver Cancer Early Detection
Liver Cancer Staging
- ▶ **American Society of Clinical Oncology:**
www.cancer.net
Liver Cancer: Stages
- ▶ **Blue Faery: The Adrienne Wilson Liver Cancer Association:**
www.bluefaery.org
Hepatocellular Carcinoma

Staging systems: Understanding your specific diagnosis and what

STAGING SYSTEM: BARCELONA CLINIC LIVER CANCER (BCLC)

Below are liver cancer staging illustrations along with the components considered by the Barcelona Clinic Liver Cancer (BCLC) staging system. They include the Child-Pugh scoring system, the most commonly used staging system for hepatocellular carcinoma, which is used to evaluate liver function, and the Eastern Cooperative Oncology Group (ECOG) Performance Status, which measures how the disease is affecting your ability to conduct daily activities.

STAGES OF LIVER CANCER



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	2.0-3.0	> (more than) 3.0
Prothrombin time (in seconds)	< (less than) 4	4-6	> (more than) 6
International Normalized Ratio (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 severe liver damage

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

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



Understanding your pathology report

➔ Your pathology report is an essential document that provides information about the unique characteristics of your liver cancer. It guides your health care team in planning the treatment most likely to be effective based on your cancer's specific features.

If a biopsy is determined necessary, your doctor may perform a percutaneous (through the skin) needle biopsy before treatment or collect a tissue biopsy following definitive surgery, which is the removal of the tumor(s). A pathology report on the specimen is prepared by a pathologist, a physician with specialized training in diagnosing disease by studying its cells under a microscope. The pathologist examines the sample (or entire tumor) with and without a microscope, documenting size and appearance, and sometimes performing special testing. The final report is based on all findings of the examination.

Diagnosing liver cancer and accurately identifying all the characteristics of the tumor(s) are challenging. The expertise of physician specialists is required because the planning of your treatment (or further treatment) will be based on the results of the pathology report.

Getting a second opinion from another pathologist with extensive experience in interpreting pathologic findings for liver cancer can be beneficial, especially if there was difficulty or controversy in interpreting the findings. Be sure to ask your doctor to seek a second opinion if the pathology report does not contain a definitive diagnosis or if your liver cancer is a rare type or has metastasized (spread). Another interpretation can confirm your diagnosis or suggest an alternative diagnosis.

Ask your doctor to go over the pathology report with you to explain any information that isn't clear to you, and be sure to get a copy of the report.

it means for your treatment plan

STAGING SYSTEM: AMERICAN JOINT COMMITTEE ON CANCER (AJCC)

The TNM staging system, developed by the American Joint Committee on Cancer (AJCC), 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 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 more than one tumor but the cancer has not yet spread beyond the liver, the tumor has spread to a major vein

around the liver, or the tumor has spread to nearby organs (except the gallbladder) or broken through the visceral peritoneum (the outer layer of the liver). In all cases, the tumor has not yet spread to regional lymph nodes or distant sites.

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

If your cancer recurs, 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 treatment 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.

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 has 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.

Metastasis



A new appreciation for life is born

➔ **Being diagnosed with Stage IIIB 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 her story to provide support and advice for others affected by this difficult cancer.**



m

y liver cancer was caught completely by accident, and oddly enough, it saved my life. In 2008, I had muscle weakness, irregular heartbeats and hallucinations, and I passed out.

Rushed to the ER, I spent the next three days in the hospital as the doctors tried to figure out what was wrong. Tests showed I had critically low levels of potassium, also known as hypokalemia.

Suspecting the hypokalemia was due to a problem with my kidneys, a nephrologist ordered a CT. Several days later he called to say my kidneys looked great, but he saw a 9 cm mass on the background of my liver. He arranged for me to see a gastrointestinal doctor.

At home, I searched online for more information, and I became very frightened. I convinced myself it was a benign mass. I didn't have any symptoms, nor did I have any of the common things that would typically cause liver cancer. I was very active and had even run a 15K the month before. I thought I was pretty healthy.

The GI doctor ordered bloodwork. On April 1, 2009, I met with her to get the results. She looked at me and told me it was serious. She grabbed a pen and paper and said, "I'm going to write all this down for you because you won't remember everything." The diagnosis was hepatocellular carcinoma (HCC). She'd tested for the tumor marker alpha-fetoprotein (AFP). In healthy people, the normal range of AFP is 0 to 5.9. Mine was 3,472.

This was no April Fool's joke. I was in shock. I was so upset that I had to call my dad to meet me in the parking lot to calm me down before I could drive myself home.

Everything I'd read said the best chance of survival was either surgery or a liver transplant, and the doctor had a direct connection to a colleague at another research-based hospital that also

had a transplant team. She sent me to get evaluated for a liver transplant, and she emphasized how great it was to have found the cancer by accident.

For two weeks, I went through a transplant evaluation and held onto the hope that I would be eligible for one. But the results showed I was not a candidate. The other option was surgical resection to remove as much of the tumor as possible.

The tumor laid over the hepatic artery, so the surgeon carefully peeled it off and cut as close as possible, knowing he wouldn't be able to ensure a completely clean margin. He also found that the tumor had focally invaded a nearby lymph node so it was removed as well. After pathology, my official diagnosis was Stage IIIB. For the next year, I was on a strict follow-up schedule to monitor for a recurrence every three months.

In June 2010, a complication from the first surgery required a second surgical resection. A blockage caused blood to back up. Approximately 40 percent of my liver had become necrotic, so the entire left lobe was surgically removed. Fortunately, over time, my liver regenerated, and scans confirm it.

During a standard checkup in October 2010, my AFP level increased to 27 and an MRI showed a 0.5 mm spot on my liver in the same area as the first. My treatment team agreed the best procedure would be chemoembolization. I admit, I freaked out because I had hoped again for a transplant, but I sought a second opinion, and those doctors agreed with mine.

The procedure was a success. I have no evidence of disease, and I continue to have follow-up appointments every six months.

Cancer was the worst thing and the best thing that ever happened to me. I have a new appreciation for life. I keep a copy of my latest blood test with my tumor marker number on the wall of my office. When stressed, I stop and look at that number and realize that being alive is what really matters. ■

➔ Anna's Recommendations

1. **Never go to appointments or scans alone.**
2. **Seek a second opinion.** They bring confidence to making decisions.
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. Remember that people who comment online are often desperate, and reviewers typically are paid for their opinions or are angry.
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.

better off bald

a life in 147 days

by ANDREA
WILSON WOODS

Adrienne Wilson is a depressed, suicidal teenager—until the day she receives a diagnosis of Stage IV liver cancer.

Adrienne Wilson is a depressed teenager—until she receives a diagnosis of advanced liver cancer. Facing the fight of her life, Adrienne discovers how much she wants to live. Adrienne squeezes more life into 147 days than most people do in a lifetime. As she lay dying, Adrienne teaches others how to live.

“*Better Off Bald* is a phenomenal depiction of the shock, horror, realities, and the humanity of a cancer diagnosis and battle. The author’s depiction of her sister’s battle with liver cancer is both heart-wrenching and warming including moments of frustration, fear, love, and exquisite human tenderness. Andrea is as brave as her sister Adrienne for sharing their story with such honesty and for her tireless devotion to helping liver cancer patients. Grab a tissue...”

—Heather Ambrose,
mom of Gavin Ambrose,
Stage IV brain cancer survivor

BOOKS-A-MILLION

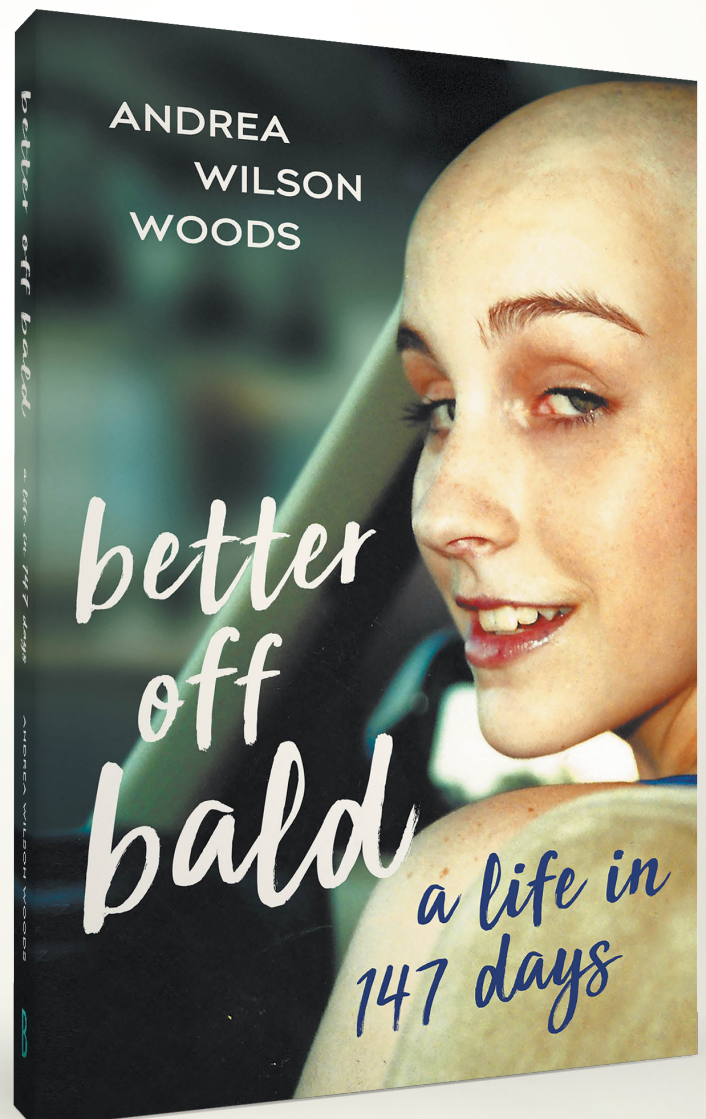
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betteroffbald.com



Understanding your treatment goal is crucial

Many things must be considered when treating HCC, which is a complex cancer in a complex organ. HCC treatment is highly personalized so the many health-related variables can be addressed. The underlying condition causing the cancer and the cancer must be treated. This requires a multidisciplinary team of specialists to plan and oversee all phases of treatment. This means doctors, nurses and other health care professionals from different medical fields will work together to provide you with the best possible care.

The therapies chosen for you will depend heavily on your liver function and your general health, so a thorough health assessment will be performed and more tests may be ordered before any recommendations are offered.

Your doctors will consider the following factors, among others:

- How much of the liver is affected, including tumor size, location and number
- Whether cancer has spread (metastasized) outside the liver
- How well the liver is working; whether noncancerous areas remain healthy
- Other serious health conditions you may have and your overall physical condition
- Your personal preferences about undergoing certain treatments and/or their potential effects on your quality of life

Treatment doesn't always mean "cure." As you and your medical team discuss treatment options, it is very important that you agree with the goal of treatment and recognize that over time, that goal may change.

Common treatment goals follow.

- Eliminate the cancer to cure HCC. This is called curative treatment.
- Shrink the tumor(s) to make liver resection or transplantation possible. This may be referred to as downstaging the tumor.
- Slow the cancer's growth or progression to extend life.
- Improve 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. This is called supportive (or palliative) care (see *Supportive Care*, page 11).

Recent breakthroughs in liver cancer research have led to more options for extending life and improving quality of life for people diagnosed at any stage. However, for individuals living with advanced or late-stage HCC, no curative treatments are currently approved by the U.S. Food and Drug Administration (FDA). Also, for many

reasons, even people diagnosed with early stage HCC may not be good candidates for receiving a curative treatment. Therefore, fully understanding what undergoing treatment potentially can – and cannot – achieve for you is essential when making decisions about your care.

COMMON TREATMENTS FOR HCC

Your medical team will likely recommend one or more of the following treatments. Particularly for people diagnosed with advanced HCC, clinical trials are an important treatment option that deserve serious consideration. These medical research studies may provide access to new investigational therapies that are not yet available to the public (see *Clinical Trials*, page 10).

Surveillance

This option may be recommended for tumors that appear to be growing very slowly. Postponing treatment while doctors closely monitor you (every three months is common) allows you to avoid potential side effects for as long as possible. It is very important to make and keep follow-up appointments because treatment should begin if the pace of cancer progression speeds up (see *Ongoing Monitoring and Care*, page 14).

Surgery

This is the primary curative method for treating HCC, through a partial hepatectomy (HEH-puh-TEK-toh-mee) or liver transplantation. Liver surgery is often complex and requires a high degree of training and skill. 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.

- Partial hepatectomy, or liver resection, 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.

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. 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.

- Liver transplantation removes the entire liver (hepatectomy) and replaces it with a healthy liver, most often from a deceased donor. It is a highly effective treatment for HCC, but 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



“/ SURVIVOR VOICE / Dave K.

“ Treatment is not just medication; it is fostering a positive environment, eating right and staying active, communicating with the medical team about side effects before they get out of hand, and not letting cancer rule your life. ”

referred to a transplantation center for assessment. 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.

Percutaneous ablation therapy

When surgery is not an option, percutaneous (passing through the skin) ablation therapy is often used to treat HCC and may be curative. This minimally invasive, image-guided procedure kills cancer cells by inserting a needle directly into the tumor and running electrical current through it to subject the tumor to extreme temperatures.

- 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

When curative treatment is not possible, embolization procedures 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 disease and reduce symptoms, though radioembolization has also been used to reduce the size of tumors to permit subsequent surgical treatment.

Molecularly targeted therapy

This treatment option is designed to slow the cancer's progression. Targeted therapy drugs travel throughout the body in 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 inhibitor, which means 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. Most of these targeted therapies are taken orally at home.

DRUG THERAPIES FOR HCC

- ▶ cabozantinib (Cabometyx)
- ▶ lenvatinib (Lenvima)
- ▶ nivolumab (Opdivo)
- ▶ pembrolizumab (Keytruda)
- ▶ ramucirumab (Cyramza)
- ▶ regorafenib (Stivarga)
- ▶ sorafenib (Nexavar)

POSSIBLE COMBINATION THERAPY

- ▶ ipilimumab (Yervoy) and nivolumab (Opdivo)

As of 4/10/20

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 target 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).

Radiation therapy

By using 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 sometimes 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. Using radiation therapy as a curative treatment for HCC is an intense research focus in clinical trials. ■



WHO'S WHO ON THE HEALTH CARE TEAM

Your multidisciplinary team may include many of the following specialists, as well as other health care professionals.

Gastroenterologist: Diagnoses and treats disorders of the gastrointestinal (GI) tract (digestive system), which includes the liver

Hepatobiliary surgeon: Specializes in surgical procedures for the liver, bile ducts, gallbladder and pancreas

Hepatologist (subspecialty of Gastroenterology): Diagnoses and treats disorders of the liver, gallbladder and pancreas. May also participate in evaluation of liver transplant candidacy

Interventional radiologist: Specializes in minimally invasive imagery-guided procedures, such as ablation and embolization

Medical oncologist: Treats cancer using medicines such as chemotherapy, targeted therapy or immunotherapy

Oncology nurse practitioner (ONP): Specializes in managing the physical and psychological needs of cancer patients and their loved ones

Oncology nurses: Provide cancer care in inpatient and outpatient settings

Palliative care specialists: Offer physical and emotional relief for cancer symptoms, treatment-related side effects, pain management and more



Patient navigator/nurse navigator: Guides people with cancer and their loved ones through diagnosis, treatment and followup; may also serve as a patient advocate

Pharmacist: A health professional who has special training in preparing and dispensing (giving out) prescription drugs

Radiation oncologist: Uses radiation therapy to treat cancer

Surgical oncologist: Specialist that treats cancer using surgical procedures

Research offers access to the newest therapies available

Medical researchers are investigating new therapies and palliative care options that are offering hope for many people diagnosed with liver cancer today. As a result, clinical trials are increasing, making it an exciting time for liver cancer research, especially for advanced stages. Clinical trials are research studies that investigate new therapies and palliative care options with the help of people who volunteer to participate.

Early-phase clinical trials typically assess optimal dose schedules and side effects. Later phase clinical trials typically assess whether or not the new (experimental) therapy is better than already existing therapies.

Current clinical trials in liver cancer are exploring various new combination therapies. Multiple trials are researching whether immunotherapy is best given alone or in combination with another therapy.

Other ongoing trials involve immune checkpoint inhibitors, vaccines and chimeric antigen receptor (CAR) T-cell therapy. Researchers are also searching for new biomarkers to determine good candidates for specific therapies.

Other clinical research includes studies of new screening methods, gene therapy, adjuvant treatment, new surgery techniques, expanding the criteria for liver transplants, determining recurrence risk after surgery and investigating better ways to reduce symptoms and side effects to improve quality of life. ■



WHAT ARE CLINICAL TRIALS?

- ➔ Clinical trials are medical research studies that are frequently used to test new therapies.
- ➔ All participants enrolled are volunteers.
- ➔ The details of a trial are outlined in the *Informed Consent* form, which participants must sign before beginning a trial.
- ➔ Participants can withdraw from a clinical trial at any time for any reason.



HOW TO FIND A CLINICAL TRIAL

- ➔ Ask your doctor about available trials for which you may qualify.
- ➔ Search online. Start with this list of clinical trial sites. Depending on your diagnosis, there could be hundreds. Ask friends and family to help.
- ➔ Have your exact diagnosis, pathology report and treatment details available to see if you meet a trial's criteria.
- ➔ Discuss possible trials with your doctor to determine whether they are an option for you.



MYTHS vs FACTS

A clinical trial is a last resort. In some situations, a clinical trial may offer the best option among treatments you're considering and may even be the first option to consider.

If my doctor doesn't bring it up, I can't participate. Many trials take place at the same time, making it very difficult for your doctor to know about every trial. That's why you're encouraged to search for a clinical trial on your own.

I'll have to travel to a major city to take part in a trial. Not necessarily. Although some people travel to take advantage of some trials, more are available all over the country in hospitals, treatment centers and doctor's offices.

Once I start the trial, I have to finish it. Participation is always voluntary. You may choose to leave the trial at any time, for any reason, and opt for standard-of-care treatment.

I'm too old to be in a clinical trial. Seniors may respond differently to treatment and may develop different side effects. Having them enrolled in a trial helps researchers develop the right treatments for older people.



BENEFITS OF PARTICIPATION

- ➔ Access to leading-edge treatments that aren't yet available for your type or stage of disease.
- ➔ Higher level of care because you will be closely monitored by your oncologist and the clinical trial medical team.
- ➔ Being an active partner in your own care.
- ➔ Knowing you are contributing to the future of cancer care.



QUESTIONS TO ASK YOUR DOCTOR

Should I consider a clinical trial?

What tests and treatments are involved?

Is travel required to participate?

Will you continue to manage my care?

Will it affect my daily life, such as my capability to work?

How long will the trial last?

CLINICAL TRIAL SITES

Blue Faery: The Adrienne Wilson Liver Cancer Association
www.bluefaery.org/clinical-trials

Center for Information & Study on Clinical Research Participation
www.searchclinicaltrials.org

CenterWatch
www.centerwatch.com

ClinicalTrials.gov
www.clinicaltrials.gov

National Cancer Institute
www.cancer.gov
Steps to Find a Clinical Trial

See more links on page 15.

Begin valuable services early to promote better quality of life

Managing the physical and emotional challenges of a liver cancer diagnosis and treatment can feel overwhelming, but support is available through your multidisciplinary team. Known as supportive care, this set of services can help you address the physical, emotional, practical, spiritual, financial and family-related challenges you may experience. A primary focus is to help you prevent, minimize and manage treatment-related side effects. Successfully managing the following symptoms and side effects can improve your quality of life.

Abdominal pain typically occurs in the stomach and may include cramping and dull aches. This type of pain can be more severe and debilitating than the occasional abdominal pain experienced by healthy individuals. Be sure to talk to your doctor openly about any abdominal pain you experience so it can be controlled.

Appetite loss (anorexia) is a common symptom of cancer and its treatments. To prevent weight loss, try to maintain a nutritious diet during and after treatment. If you cannot eat enough food to maintain your weight, talk to your doctor.

Ascites is a condition in which an abnormal amount of fluid collects in the peritoneal (abdominal) cavity. Ascites can be malignant, meaning it's caused by cells distributed throughout the abdominal cavity, or non-malignant, meaning it's 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.

Bleeding problems (hemorrhages) and bruising may occur. Tell your doctor if you have a history of bleeding problems. If you experience any of these symptoms, contact your doctor immediately: blood in your stools or black stools (looks like tar); pink or brown urine; unexpected bleeding or severe bleeding that you cannot control; vomit that looks like coffee grounds; coughing up blood or blood clots; increased bruising, dizziness,

weakness or confusion; changes in speech; or a headache that lasts a long time.

Cognitive dysfunction involves problems with normal thinking processes, such as thinking clearly, finding the right word or remembering names, dates and other details. Although this may result from chemotherapy, it can also result from underlying liver disease (such as cirrhosis). If you are experiencing problems with cognitive decline, talk with your doctor regarding treatments that may be employed to reduce this symptom. Some patients are given antibiotics to reduce gut bacteria, as these bacteria create toxins that the liver must try to handle. Use a planner or calendar and carry it with you. Make to-do lists, and focus on one thing at a time instead of multitasking.

Diarrhea can seriously affect your quality of life. If diarrhea causes distress or keeps you homebound, tell your doctor, who may check for a *Clostridium difficile* (C. diff) colon infection. Severe diarrhea can lead to dehydration and loss of essential nutrients. Ask about preventive medications and how to rest your bowels, which can reduce and ultimately eliminate symptoms.

Dysphonia (impaired voice) is a disorder that may include difficulty speaking or swallowing, hoarseness, raspy voice, soft voice, no voice or swelling in the throat. Call your doctor if you suddenly lose your voice, have severe pain in your throat or a fever of 100.5°F or higher or as directed by your doctor.

Dyspnea is the medical term for difficult or labored breathing or shortness of breath. Some patients describe it as a feeling of breathlessness. Talk to your doctor immediately if you experience any symptoms.

Fatigue related to treatment lasts longer than typical tiredness, is more severe and may not be relieved by sleep. Make sure your doctor is aware of your fatigue so that possible underlying causes, such as anemia or depression, can be addressed or ruled out. Exercise is a proven fatigue fighter.

Hair loss (alopecia) may occur on your head, face and body because certain treatments destroy rapidly growing cells. For a wig, ask your oncologist for a prescription for a "cranial prosthesis due to alopecia from cancer treatment," as this phrasing may make it eligible to be partially or fully covered by health insurance.

Hand-foot syndrome, also known as Palmar-Plantar Erythrodysesthesia, is characterized by pain, swelling, tightness and redness on the palms of the hands or the soles of the feet. It can also cause painful blisters or calluses. Avoid hot water for bathing or washing dishes, and wear gloves or thick socks to protect hands and feet. Talk to your doctor as soon as you begin experiencing symptoms.

Hepatic encephalopathy occurs when the liver is unable to filter toxins in the blood sufficiently. The buildup of these toxins affects the brain and nervous system's ability to function. Ask your doctor for symptoms to watch for and when to go to the emergency room.

Hypertension is abnormally high blood pressure. Over time, the elevated force of the blood on the arteries is so great that it causes small tears in the artery walls. Plaque (small particles of fat, cholesterol and other substances) then gets stuck in the tears and builds up, which slows blood flow to the heart, brain, kidneys, arms and legs.

Immune-related adverse events (irAEs) are serious side effects of some immunotherapy treatments, including checkpoint inhibitors. An irAE can cause inflammation in different organs and systems, and initial signs may include redness or swelling and/or a fever. Symptoms can develop rapidly and in some cases become severe, even life-threatening.



“ CAREGIVER VOICE / Wendy K.

“My husband's cancer was caught early because he kept his follow-up appointments after Hepatitis C treatment. If he'd skipped those blood tests and scans, the tumor would not have been found until he had physical symptoms. Now that he's in treatment for his liver cancer, we stay in constant contact with his medical team. We feel that's helped keep his side effects in check, and it offers us peace of mind.”

without emergency medical attention. Report symptoms immediately to your doctor for up to two years following immunotherapy.

Infection can occur as a result of low white blood cell count (neutropenia). Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.5°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.

Joint pain (arthralgia), **muscle pain** (myalgia) and **pain** in general may be related to treatment, the cancer itself or the underlying liver condition. Many pain management strategies are available, so contact your doctor or nurse right away if you are in pain.

Mouth sores (oral mucositis) may affect the gums, tongue, roof of mouth and/or lips. Pain may range from mild to severe, making it difficult to talk, eat or swallow. Ask your doctor about medications to prevent or minimize this condition.

Nausea and vomiting may be prevented with antiemetics (anti-nausea drugs) before treatment begins. Contact your doctor about any of these serious symptoms: more than three episodes of vomiting an hour for at least three hours; blood in vomit; vomit resembling coffee grounds; inability to drink more than eight cups of fluid or ice chips in 24 hours; inability to eat solid food for more than two days; weakness or dizziness; or inability to keep medications down.

Skin reactions can include redness and irritation (similar to sunburn), rash, itching or dry, flaky skin. Most symptoms are mild to moderate, but some can be severe or even life-threatening without early treatment. If you have neutropenia (low white blood cell count) when reactions occur, seek immediate medical attention. ■

Understanding why palliative care is so important

L

iver cancer is often accompanied by serious complications, especially as the disease progresses. It is crucial to talk with your doctor soon after diagnosis so you can have a plan in place to help manage these complications. The foundation of this plan is known as palliative care.

Also referred to as supportive care, this valuable set of resources is available to assist you and your caregiver. Palliative care spans a wide range of services and employs many different specialists from your multidisciplinary team. It may include educating you about your illness and prognosis, managing symptoms and quality-of-life issues, offering psychosocial support, coordinating care among the health professionals, helping with advance care planning and assisting caregivers. It is recommended you seek assistance soon after diagnosis because the course of liver disease is difficult to predict. 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.

As the disease progresses, you may need the services of an oncology nurse navigator, who will be key in accessing palliative care services. This person is your liaison with the health care team who can coordinate your care with other specialists, find psychosocial support services, provide survivorship or end-of-life services or care transitions, find community resources and be your advocate. The navigator can also identify a need for home-based care, screen for other unrelated health conditions and assist with hospice referral.

Some physical side effects can become much more serious as liver cancer advances. 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. This is known as hepatic encephalopathy. You may need assistance to understand the prognosis and make decisions about treatment and quality of life or advance care planning, and palliative care specialists can help.

Another serious side effect of advanced liver cancer as well as cirrhosis is an accumulation of fluid in the abdominal cavity known as ascites. The fluid buildup causes abdominal pain and may make it difficult to breathe. To relieve the discomfort, your doctor may perform a large volume paracentesis, which is a procedure to remove the fluid. If intermittent paracentesis is needed for symptom relief that will be ongoing, the doctor will place a catheter through the abdomen and into the peritoneal cavity so that the fluid can be drained at home. Your nurse will show you how to clean and change the catheter and dispose of the fluids.

Your emotional well-being may be at risk. It is common for people with liver cancer to experience feelings of anxiety, depression, sadness, anger, isolation and hopelessness, among many other emotions, which may require ongoing monitoring. You and your caregiver must notify your health care team if your distress becomes excessive and any of the following symptoms occur:

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

You don't need to face these emotional challenges alone. Psychosocial services are available to assist you and your caregiver through this challenging time and may include referrals to mental health specialists, religious or faith-based resources or support groups. Your doctor may consider medications or alternatives, such as cognitive-behavioral therapy, relaxation practices, guided imagery, meditation, yoga and tai chi.

HAND WASHING FOR PATIENT SAFETY



1 Wet your hands



2 Soap



3 Lather and scrub



4 Rinse



5 Dry your hands



6 Turn off tap

Don't forget to wash

- Between your fingers
- Under your nails
- The tops of your hands

→ For additional copies, go to: PatientResource.com/HandWashing.aspx

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How to embrace this rewarding yet demanding role

As a caregiver for someone with liver cancer, you are about to take on many new responsibilities. If you feel unprepared for this role, you're not alone. Few people believe they have the training necessary to be a caregiver. And if you aren't familiar with liver cancer, your new role may be even more challenging. These suggestions may help.

Liver cancer is often referred to as a disease within a disease, which means your loved one will be treated for both liver cancer and the underlying condition that contributes to it. That may mean more medical appointments, multiple medications and many side effects.

Learn as much as you can about this diagnosis. Ask your loved one's doctor to help you be aware of what to watch for.

You will be a valuable asset in many ways:

- Scheduling and transporting to frequent medical appointments.
- Taking notes during doctor's appointments.
- Tracking and possibly giving medications and ensuring they are taken as prescribed.
- Monitoring for signs of infection and other complications.
- Managing treatment-related side effects.



- Caring for drains and ports, if applicable.
- Preparing nutritious food that helps the liver work more efficiently.
- Recognizing jaundice and/or cognitive issues that are caused by a buildup of toxins if the liver is not functioning adequately.
- Ask the doctor what to watch for, and be aware that as liver cancer progresses, symptoms will change.

- Communicating with the multidisciplinary health care team in person, by phone or through an online portal. Make sure your loved one has added you as a person with whom the medical team may communicate about your condition.
- Updating concerned family and friends.
- Offering emotional support, and seeking it for yourself. The stigma surrounding liver cancer increases the caregiver burden considerably. Because liver cancer is sometimes linked with risky lifestyle choices such as viral hepatitis or alcoholism, you may feel embarrassed or even worse, ashamed. Regardless of your loved one's circumstances, no one deserves a cancer diagnosis, and neither of you should carry that emotional weight. It is important to connect with other caregivers in the liver cancer community, online or locally. They understand what you're going through, and they may be an incredible source of support. Ask your health care team and use the resources in *Assistance*, page 15, to find an advocacy group. ■

Why you need to treat others the way they want to be treated

By **Andrea J. Wilson**, president & founder,
Blue Faery: The Adrienne Wilson Liver Cancer Association

➔ **When my 15-year-old sister Adrienne was diagnosed with Stage IV liver cancer, I was devastated. I was Adrienne's legal guardian, and I had raised her from the age of eight. The following story is an excerpt from my memoir "Better Off Bald: A Life in 147 Days."**

The Support Group

Every week, Teen Impact met at the hospital. Their mission was to improve the quality of life for young adults with cancer. I encouraged my sister to attend one meeting, and she agreed to shut me up.

I told her, "We'll walk in. If you hate it, we'll walk out."

She frowned.

We found the meeting in a large room where chairs were positioned in a circle. Many teenagers had already arrived. We sat in the two chairs closest to the door. A woman encouraged everyone to introduce themselves.

"We have new people here today," she said. Adrienne glared at me.

Most of the kids had leukemia. An upbeat, 16-year-old Hispanic girl had a tumor in her thigh. She sat in a wheelchair next to Adrienne.

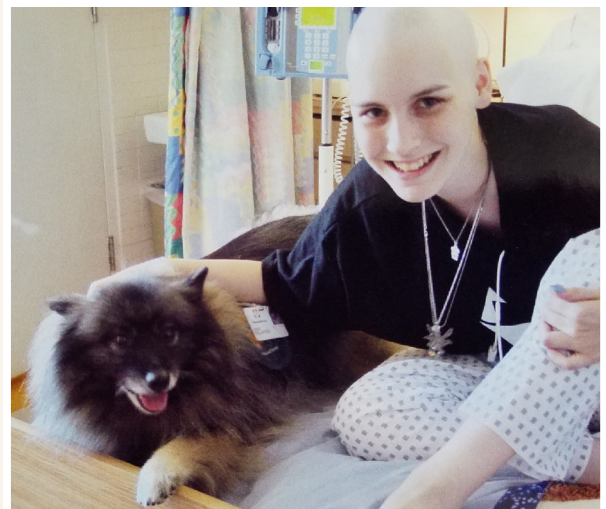
When it was her turn, Adrienne whispered, "Hello. My name is Adrienne."

Some kids responded with an enthusiastic "Hi Adrienne."

Adrienne ran out of the room in tears. I apologized and left too. Farther down the hall, I found her sitting on the floor, knees tucked into her chest, shaking and crying.

"Don't make me go back," she said.

I had pushed her too hard. She did not need or want a support group. I did.



Between sobs, Adrienne said, "I can't be around other sick kids. It's too depressing."

The Lesson

The golden rule – to treat others the way we want to be treated – does not work with cancer. With Adrienne, I learned to treat her the way she wanted to be treated. When her desires conflicted with mine, I would remind myself I wasn't the one with cancer. Adrienne was the patient, and what the patient wants is what matters most.

Communication is key for follow-up care

Whether you've finished treatment for liver cancer or are still receiving it, you will continue to be monitored through a follow-up care plan. These appointments give you the opportunity to keep the lines of communication open with your health care team and to address any new symptoms or concerns. You may continue to see several specialists, which include oncologists, hepatologists and your primary care physician, as well as others.

Regular monitoring is especially important when you have liver cancer because it can be difficult to treat. It is often accompanied by other diseases, has multiple side effects and may return after treatment. A follow-up care plan is designed to do the following.

- Monitor treatment effectiveness
- Watch for side effects and late effects
- Treat other health complications
- Screen for a recurrence or second cancers
- Evaluate mental and emotional health
- Provide palliative care

It is important to tell your doctor how you're feeling physically, mentally and emotionally at follow-up appointments or sooner if something changes. Specific important information to share at these appointments includes the following.

- New or ongoing pain that isn't 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 such as 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
- Any homeopathic or naturopathic therapies you have started

A follow-up care plan will also include instructions for maintenance medications; referrals for cancer rehabilitation services, such as physical or occupational therapy; information about your risk of a recurrence or second cancer; and recommended screening guidelines for other types of cancer.

SURVIVORSHIP CARE PROGRAMS

If treatment has ended and your doctor wants

to continue monitoring you, a survivorship care program may be offered. Doctors are not required to give you a survivorship care plan, but cancer centers now provide survivorship educational programs about ongoing care. They can be helpful as you transition to life after treatment.

A survivorship care 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 the follow-up care plan you receive does not include recommendations for survivorship care, your doctor, nurse navigator or caseworker can help you make one. This information may also include referrals and ongoing support for emotional needs, side effects and late effects and any research that may be appropriate for you.

To help you create a personalized survivorship care plan, visit PatientResource.com/SurvivorshipPlan.aspx to download a Survivorship Diagnosis Care Summary and Follow-up Care Plan. ■



Know your medications

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. So, preventing further damage to your liver will be crucial throughout and after treatment. That includes being careful about which medications and supplements you take in order to prevent interference with medications prescribed by your physicians or toxicity to your liver.

Ask your doctor about any prescription or over-the-counter medications or supplements that you should avoid taking during or after treatment. A list of active ingredient names can help you identify these drugs.

Some general steps to follow:

- Read all medicine labels and look at the active ingredient.
- Find out if your doctor recommends any limit on the amount of acetaminophen.
- Check the label for acetaminophen and its shorter versions "APAP" or "acetam."
- Ask your doctor how to read medication labels if you're not familiar with them.
- Check with your pharmacist every time you start, stop, change or fill a prescription.
- Take your medicine as directed.
- Use the same pharmacy each time so workers can help you keep track of what you're taking.
- Do not take medicine that has expired.
- Do not take or share medicines with others.
- Only take the recommended dose. Do not take more.
- Refill your prescriptions before they run out.
- 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

BASIC LIVING EXPENSES

Bringing Hope Home.....	www.bringinghopehome.org, 484-580-8395
Cleaning for a Reason (free house cleaning service).....	www.cleaningforareason.org, 877-337-3348
Family Reach Foundation.....	www.familyreach.org, 973-394-1411
Life Beyond Cancer Foundation.....	www.needhelppayingbills.com, 800-282-5223

CANCER EDUCATION

American Cancer Society.....	www.cancer.org
American Society of Clinical Oncology.....	www.cancer.net
CANCER101.....	www.cancer101.org
CancerCare.....	www.cancer.org
CancerQuest.....	www.cancerquest.org
Cancer Support Community.....	cancersupportcommunity.org
Centers for Disease Control and Prevention (CDC).....	www.cdc.gov
The Gathering Place.....	www.touchedbycancer.org
Get Palliative Care.....	www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE).....	www.cancergrace.org
The Hope Light Foundation.....	hopelightproject.com
Livestrong Foundation.....	www.livestrong.org
National Cancer Institute.....	www.cancer.gov
National Comprehensive Cancer Network (NCCN).....	www.nccn.org
National LGBT Cancer Network.....	cancer-network.org
NCI Contact Center (cancer information service).....	800-422-6237
Oncolink.....	www.oncolink.org
Patient Power.....	www.patientpower.info
PearlPoint Nutrition Services.....	www.pearlpoint.org
Pine Street Foundation.....	pinestreetfoundation.org
Scott Hamilton Cares Foundation.....	www.scottcares.org
Triage Cancer.....	triagecancer.org
U.S. National Library of Medicine.....	www.nlm.nih.gov

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program.....	www.4thangel.org
CanCare.....	www.cancare.org
CANCER101.....	www.cancer101.org
Cancer and Careers.....	www.cancerandcareers.org
CancerCare.....	www.cancer.org
Cancer Connection.....	www.cancer-connection.org
Cancer Hope Network.....	www.cancerhopenetwork.org
Cancer Information and Counseling Line.....	800-525-3777
Cancer Really Sucks!.....	www.cancerreallysucks.org
Cancer Support Community.....	cancersupportcommunity.org
Cancer Support Helpline.....	888-793-9355
Cancer Survivors Network.....	csn.cancer.org
Caregiver Action Network.....	www.caregiveraction.org
CaringBridge.....	www.caringbridge.org
Center to Advance Palliative Care.....	www.capc.org
Chemo Angels.....	chemoangels.com
Cleaning for a Reason.....	www.cleaningforareason.org
Connect Thru Cancer.....	www.connectthrucancer.org
Cooking with Cancer.....	www.cookingwithcancer.org
Family Caregiver Alliance.....	www.caregiver.org
Fighting Chance.....	www.fightingchance.org
Friend for Life Cancer Support Network.....	www.friend4life.org, 866-374-3634
The Gathering Place.....	www.touchedbycancer.org
Guide Posts of Strength, Inc.....	www.cancergps.org
The Hope Light Foundation.....	hopelightproject.com
Imerman Angels.....	www.imermanangels.org
Livestrong Foundation.....	www.livestrong.org
LivingWell Cancer Resource Center.....	www.livingwellcrrc.org
Lotsa Helping Hands.....	www.lotsahelpinghands.com
The Lydia Project.....	thelydiaproject.org
MyLifeLine.org.....	www.mylifeline.org
Patient Empowerment Network.....	www.powerfulpatients.org
Patient Power.....	www.patientpower.info
SHARE Caregiver Circle.....	www.sharecancersupport.org/caregivers-support
Stronghold Ministry.....	www.mystronghold.org
Support Groups.....	www.supportgroups.com

Triage Cancer.....	www.triagecancer.org
Vital Options International.....	www.vitaloptions.org
Walk With Sally.....	www.walkwithsally.org
Well Spouse Association.....	www.wellspouse.org
weSPARK Cancer Support Center.....	www.wespark.org

CLINICAL TRIALS

ACT (About Clinical Trials).....	www.learnaboutclinicaltrials.org
Blue Faery: The Adrienne Wilson Liver Cancer Association.....	www.bluefaery.org/clinical-trials
Cancer Support Community.....	cancersupportcommunity.org
Center for Information & Study on Clinical Research Participation.....	www.searchclinicaltrials.org
CenterWatch.....	www.centerwatch.com
ClinicalTrials.gov.....	www.clinicaltrials.gov
Exelixis.....	www.exelixis.com/access/
Lazarex Cancer Foundation.....	www.lazarex.org
Livestrong Foundation.....	www.livestrong.org
National Cancer Institute.....	www.cancer.gov/clinicaltrials

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big.....	www.believebig.org
National Center for Complementary and Integrative Health.....	www.nccih.nih.gov
Office of Cancer Complementary and Alternative Medicine.....	cam.cancer.gov
Society for Oncology Massage.....	www.s4om.org

FERTILITY & CANCER

Alliance for Fertility Preservation.....	www.allianceforfertilitypreservation.org
American Society for Reproductive Medicine.....	www.reproductivefacts.org
Livestrong Foundation.....	www.livestrong.org
RESOLVE: The National Infertility Association.....	www.resolve.org
SaveMyFertility.....	www.savemyfertility.org

FINANCIAL ASSISTANCE

American Cancer Society (Hope Lodge).....	www.cancer.org/hopelodge, 800-227-2345
BenefitsCheckUp.....	www.benefitscheckup.org
Bringing Hope Home.....	www.bringinghopehome.org
CancerCare.....	www.cancer.org/financial
Cancer Financial Assistance Coalition.....	www.cancerfac.org
HealthWell Foundation.....	www.healthwellfoundation.org
Medicare.gov.....	www.medicare.gov
Medicine Assistance Tool.....	medicineassistancetool.org
NeedyMeds.....	www.needymeds.org
Patient Access Network Foundation.....	www.panfoundation.org
Patient Advocate Foundation.....	www.patientadvocate.org
Patient Services, Inc.....	www.patientservicesinc.org
RxAssist.....	www.rxassist.org
RxHope.....	www.rxhope.org
Social Security Administration.....	www.ssa.gov
Social Security Disability Resource Center.....	www.ssdrc.com
State Health Insurance Assistance Programs.....	www.shiptacenter.org

GOVERNMENT ASSISTANCE

Benefits.gov.....	www.benefits.gov, 800-333-4636
Centers for Medicare & Medicaid Services.....	www.cms.gov
Disability Benefits Center.....	www.disabilitybenefitscenter.org
Eligibility.com (Medicare resources).....	eligibility.com/medicare/resources
Hill-Burton Program.....	www.hrsa.gov/get-health-care/affordable/hill-burton, 800-638-0742
Legal Services Corporation.....	www.lsc.gov, 202-295-1500
Medicare Rights Center.....	www.medicarerights.org, 800-333-4114
National Council for Aging Care.....	www.ncoa.org, 571-527-3900
Social Security Administration.....	www.ssa.gov, 800-772-1213
State Health Insurance Assistance Programs.....	www.shiptacenter.org
U.S. Department of Veterans Affairs.....	www.va.gov/health

HOSPICE & HOME CARE

American Hospice Foundation.....	www.americanhospice.org
CaringInfo.....	www.caringinfo.org
Hospice Foundation of America.....	www.hospicefoundation.org
International Association for Hospice and Palliative Care.....	www.hospicecare.com

National Association for Home Care & Hospice	www.nahc.org
National Hospice and Palliative Care Organization	www.nhpco.org
The Oley Foundation	www.oley.org
Visiting Nurse Associations of America	www.vnaa.org

HOUSING DURING TREATMENT EXPENSES

American Cancer Society (Hope Lodge)	www.cancer.org/hopelodge, 800-227-2345
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
Hotel Keys of Hope	www.extendedstayamerica.com/acs-partnership, 800-804-3724
Joe's House	www.joeshouse.org, 877-563-7468

INSURANCE PREMIUM EXPENSES

CancerCare Co-Payment Assistance Foundation	www.cancerarecopay.org, 866-552-6729
HealthWell Foundation (diagnosis-specific)	www.healthwellfoundation.org, 800-675-8416
Kaiser Family Foundation	kff.org/health-costs/report/a-consumer-guide-to-handling-disputes-with-your-employer-or-private-health-plan
Patient Advocate Foundation Co-Pay Relief	www.copays.org, 866-512-3861
Patient Services, Inc.	www.patientservicesinc.org, 800-366-7741

LEGAL ISSUES

American Bar Association	www.americanbar.org, 800-285-2221
Cancer and Careers	www.cancerandcareers.org, 646-929-8032
Disability Rights Legal Center	drlcenter.org, 866-999-3752
LawHelp.org	www.lawhelp.org
Legal Services Corporation	www.lsc.gov, 202-295-1500
National Coalition for Cancer Survivorship	www.canceradvocacy.org, 877-622-7937
National Council for Aging Care	www.aginginplace.org, 877-664-6140
National Health Law Program (links to assistance programs)	www.healthlaw.org, 202-289-7661
Patient Advocate Foundation	www.patientadvocate.org, 800-532-5274
Social Security Disability Resource Center	www.ssdrc.com

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.cancerexperienceregistry.org
Global Liver Institute	www.globalliver.org
Say YES to Hope	www.beatlivertumors.org, Survivor Hotline 877-937-7478

MEDICAL CARE EXPENSES

CancerCare	www.cancerare.org, 800-813-4673
Cancer Warrior, Inc.	www.cancerwarriorinc.org, 702-546-8575
Patient Access Network Foundation	www.panfoundation.org, 866-316-7263
Patient Advocate Foundation	www.patientadvocate.org, 800-532-5274

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline	866-276-7443
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NUTRITION

American Cancer Society	www.cancer.org
CancerCare	www.cancerare.org
Cancer Support Community	cancersupportcommunity.org
Livestrong Foundation	www.livestrong.org
OncoLink	www.oncolink.org
PearlPoint Nutrition Services	www.pearlpoint.org
Physicians Committee for Responsible Medicine	www.pcrm.org/health/cancer-resources

PAIN MANAGEMENT

American Chronic Pain Association	theacpa.org
American Society of Anesthesiologists	www.asahq.org
Cancer Pain Research Consortium	cancerpainresearch.com
Livestrong Foundation	www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives	www.trc.wisc.edu
U.S. Pain Foundation	uspainfoundation.org

PRESCRIPTION EXPENSES

America's Pharmacy	americaspharmacy.com, 888-495-3181
CancerCare Co-Payment Assistance Foundation	www.cancerarecopay.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	medicineassistancetool.org
National Organization for Rare Disorders	rarediseases.org, 203-744-0100
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
RxOutreach	rxoutreach.org, 888-796-1234
Singlecare	www.singlecare.com, 844-234-3057
Together Rx Access	www.togetherrxaccess.com, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Bayer US Patient Assistance Foundation	patientassistance.bayer.us, 866-228-7723
Bristol-Myers Squibb	www.bms.com/patient-and-caregivers/get-help-paying-for-your-medicines.html
Bristol-Myers Squibb Access Support	bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation	bmspaf.org, 800-736-0003
Cabometyx EASE	www.cabometyx.com/financial-support, 844-900-3273
Cyramza PatientOne	www.cyramza.com/financial-assistance, 866-472-8663
Eisai Reimbursement Resources	eisaireimbursement.com
Genentech	www.gene.com/patients/financial-support
Genentech Access Solutions	genentech-access.com/patient, 866-422-2377
Genentech BioOncology Co-pay Assistance Program	copayassistancenow.com, 855-692-6729
Genentech Patient Foundation	gene.com/patients/patient-foundation, 888-941-3331
Keytruda Patient Assistance	merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Lenvima Reimbursement Resource	eisaireimbursement.com/patient/lenvima, 866-613-4724
Lilly Cares Foundation Patient Assistance Program	lillycares.com, 800-545-6962
Lilly PatientOne	lillypatientone.com, 866-472-8663
Merck Access Program	merckaccessprogram.com/hcc/
Merck Helps	merckhelps.com, 800-727-5400
Nexavar Financial Support	nexavar-us.com/reach-financial-support/, 866-639-2827
Opdivo with You	patientsupport.bmscustomerconnect.com/opdivo-with-you-registration, 855-673-4861
Stivarga Reach Program	www.stivarga-us.com/getting-and-paying/, 866-639-2827

STOPPING TOBACCO USE

American Cancer Society	www.cancer.org
BecomeAnEx	www.becomeanex.org
National Cancer Institute Smoking Quitline	877-448-7848
Smokefree.gov	smokefree.gov
SmokefreeTXT	smokefree.gov/smokefreetxt

TRANSPORTATION & TRAVEL RESOURCES

The Air Care Alliance	www.aircarealliance.org, 888-260-9707
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 Airline Samaritans	www.angelairlinesamaritans.org, 888-675-1405
Angel Flight Central	www.angelflightcentral.org, 866-569-9464
CancerCare	www.cancerare.org, 800-813-4673
Chai Lifeline	www.chailifeline.org, 877-242-4543
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
Hotel Keys of Hope	www.extendedstayamerica.com/acs-partnership, 800-804-3724
Joe's House	www.joeshouse.org, 877-563-7468
Lifeline Pilots	www.lifelinepilots.org, 800-822-7972
Mercy Medical Angels	www.mercymedical.org, 757-318-9174
Operation Liftoff	www.operationliftoff.com
Patient Access Network Foundation	www.panfoundation.org, 866-316-7263
Patient AirLift Services	www.palservices.org, 888-818-1231
Veterans Airlift Command	www.veteransairlift.org, 952-582-2911

➔ For more resources, go to PatientResource.com

 **CANCER EXPERIENCE
REGISTRY.**

Liver Cancer



What is the

CANCER EXPERIENCE REGISTRY?

The Cancer Experience Registry is a research survey to understand the personal experiences of people impacted by liver cancer. By joining, you will help the cancer community gain insights about the social and emotional needs of liver cancer patients, families, and caregivers.

Who can join?

Anyone who has ever been diagnosed with liver cancer as well as relatives or friends who assist with their care is invited to join.

Why participate?

Your participation helps us understand the issues that are important to the liver cancer community, and deliver improved services to those affected by cancer.

HOW DO I JOIN?

- 1) Go to www.cancerexperienceregistry.org
- 2) Register and complete your profile
- 3) Fill out the survey

This patient education guide was produced with support from:

