# Coping with the Stigma of Liver Cancer





Being diagnosed with cancer can affect you physically, socially, and emotionally. It can disrupt your normal routine, cause you emotional concern, and change how you are used to feeling. A liver cancer diagnosis can impact both you and your loved ones in many of these ways.

Liver cancer is a cancer that forms from the tissues of the liver. The liver is one of the largest organs in the body. It is on the right side of the body, protected by the rib cage. Liver cancer is rarely diagnosed early which can change treatment options and the chance for treatment options that cure the disease may be limited.

Signs of liver cancer include abdominal pain, discomfort, decreased appetite/weight loss, and swelling in the abdomen. You may notice changes in bowel movements and yellowing of the skin or eyes called jaundice.

As with any cancer diagnosis, liver cancer can have emotional impacts. A diagnosis of liver cancer can cause feelings of sadness, fear, and worry for the future. In some cases, you may feel like you are treated differently because of your diagnosis. Many people living with liver cancer feel that they must explain the cause of their condition to others. You may feel that you are unfairly judged. The feeling that society has these thoughts about you, even when they go unsaid, is called "stigma." It is unfortunate that these ideas are often based on stereotypes. This stigma can lead to feelings of shame, guilt, and isolation. No one with a cancer diagnosis should feel ashamed, questioned, or unfairly judged.

This resource will provide information and support about stigma, its association with liver cancer, and who to speak with about these concerns.

# CHALLENGES OF LIVER CANCER STIGMA

Anyone can be diagnosed with liver cancer. Liver cancer stigma is especially unique because liver cancer may be associated with lifestyle and personal choices. These can include smoking, drug use, or drinking alcohol. Other causes, including environmental and other medical conditions are also reported. Liver cancer can also be associated with other conditions.

# THESE INCLUDE:

Hepatitis, which can be transmitted sexually or through IV drug use

Alcohol related cirrhosis

**Environmental issues** 

Long-term prescription drug usage, including medications for asthma and other chronic conditions.



Stigma can affect how you feel about yourself or how you think others feel about you. No one should be judged, nor should they feel responsible for their cancer. You should not let the possibility of stigma impact your treatment plan.

Stigma is harmful as it can keep people from seeking medical help. This may be because they fear judgement. This can come from healthcare professionals, friends, family, or others. Stigma often delays diagnosis. This can lead to poorer outcomes. Early diagnosis and treatment of liver cirrhosis or hepatitis infections can reduce the risk of developing liver cancer.



# THE STIGMA OF LIVER CANCER CAN PRESENT SEVERAL CHALLENGES FOR YOU:

- **Delayed Diagnosis and Treatment** Stigma may have prevented you from seeking medical care. It may have been a reason that symptoms were ignored. These factors can lead to delayed diagnosis and treatment, making the disease more dangerous and causing difficulties with treatment.
- **Emotional Distress** Feelings of shame, guilt, and isolation can contribute to emotional distress. Distress is an unpleasant state that can affect how you think, feel, and act. Distress can include different emotions like fear, sadness, anger, and worry.

You may also experience anxiety or depression because of stigma. Anxiety is a feeling of uneasiness, worry, or fear that usually occurs because of stress. Depression is a diagnosed condition. It causes a persistent feeling of sadness or loss of interest in things you once enjoyed.

- **Social Isolation** Stigma may lead to social withdrawal and isolation. If you feel misunderstood or judged by others, there may be a tendency to remove yourself from social settings. If you feel that people have assumptions about the cause of your cancer, it can feel easier to avoid others or hide your diagnosis all together.
- Impact on Relationships Stigma can strain relationships with family, friends, and coworkers. You may fear judgement or rejection from these people. This can impact your confidence and openness.

#### COPING STRATEGIES: WHAT YOU CAN DO

While coping with the stigma of liver cancer can be challenging, there are strategies that you can learn and use to help you manage and overcome this.

# **EDUCATION AND AWARENESS:**

Educating yourself and others about liver cancer can help correct myths. This can reduce stigma. The truth is that no one knows the cause of their cancer. No one deserves cancer. While there are factors that can contribute to the development of liver cancer, it is not your fault.

# **OPEN COMMUNICATION:**

Talking openly with loved ones about your experience with liver cancer can help increase support. Sharing how you feel can be healing and help you change your own thoughts and feelings. Many people with liver cancer may feel that their diagnosis is their fault. Regardless of any history of alcohol or drug use, you deserve care and compassion. Your care team may ask about your history with drugs and alcohol. They may be asking because this can impact treatment options. It is important to respond honestly. If you feel your care team is not treating you with dignity and respect, advocate for yourself. Talk to your care team about your concerns. You do not need to continue working with a care team if you are being mistreated. Consider seeing a different provider and seeking a second opinion. If you are being asked questions that feel judgmental or uncomfortable:

Talk about the emotional impact of their questions

Advocate for yourself by sharing information about liver cancer from trusted resources

Remind people that you can never know why you got liver cancer, but you do need their support and empathy



#### SEEKING SUPPORT:

Connecting with support groups or counseling services can provide a safe space. These options make it easier to share your experience. Others attending these groups may be experiencing similar situations and can provide emotional support. Many support groups are offered in person and virtually at no cost, making them very accessible. Speaking with a professional, such as a social worker, counselor, or religious/spiritual leader, can be extremely helpful for people. These professionals are trained to listen actively. They can provide a wealth of resources, strategies, and skills to improve quality of life and the way you see yourself.

#### **SELF-COMPASSION:**

Practicing self-compassion and self-care can help you cope with feelings of shame or guilt. Stigma creates these feelings in many cases, but allowing yourself grace and forgiveness can be freeing.

Make time for yourself to feel every emotion you have. Let yourself know it is okay to feel that way. Talk with your network of support to see if they have felt that way. What did they do to cope? What can they do to help you cope? Who could support you with these emotions?

Above all, allow yourself to feel and move on stronger. Your experiences can be a source of strength and empowerment. Treating yourself gently, acknowledging the impact this has on your physical and emotional well-being, are key to the success of your journey through liver cancer



# **ADVOCACY:**

Advocating for yourself and others affected by liver cancer can help raise awareness and reduce stigma. Get involved with places like Cancer Support Community that have support groups and activities. Consider a peer support program where you can share and learn from people with a similar diagnosis. Your cancer center may be a great place to meet others with shared experiences.

Coping with the stigma of liver cancer is an important part of managing the disease. By knowing about stigma, addressing challenges, and using coping strategies, you can improve your quality of life during your care and after treatment. Cancer care teams are prepared to help you and your loved ones after diagnosis. Throughout your care, they may check in with you about your mental health. Your care team can connect you with mental health specialists. These people can help you talk through your feelings, understand what you are experiencing, and develop skills to cope.

Some people may think that only someone experiencing severe mental health challenges should seek help. This is not true. Everyone deserves to have good mental health. You do not need to wait for your mental health to reach a certain "level" before getting help. Learn more about Mental Health and Cancer at www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.



Stigma is real and you are not alone. Talk about your feelings and seek help when needed. It is important that you do not blame yourself for your diagnosis. Use what you have learned to help yourself and others and become stronger. It is important to remember that from diagnosis, through treatment, and beyond, you deserve compassion, understanding, and care.

# THE NATIONAL SUICIDE PREVENTION LIFELINE

This is the dialing code for the U.S. National Suicide Prevention Lifeline. Those in the U.S. can call, text, or chat 988 to connect with trained counselors. This is free and confidential support in suicidal crisis or emotional distress. Visit **988lifeline.org** for more information.

Individuals in Canada can call the Suicide Prevention Service at 833-456-4566 or text 45645 between 4pm and midnight to connect with a crisis responder. These are free resources for mental health and crisis support.



# MENTAL HEALTH RESOURCES (U.S.)

# **Cancer Support Helpline**

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Cancer Support Community - 1-888-793-9355 · www.CancerSupportCommunity.org

National Alliance on Mental Illness - 1-800-950-NAMI (6264) · www.NAMI.org

American Cancer Society - 800-227-2345 · www.Cancer.org

MentalHealth.gov - www.MentalHealth.gov

National Alliance for Caregiving - www.Caregiving.org

National Cancer Institute - www.Cancer.gov/About-Cancer/Coping/Feelings

National Suicide Prevention Hotline (U.S.) - 800-273-8255 or 988

Substance Abuse and Mental Health Services Administration 1-800-662-HELP (4357) · www.SAMHSA.gov

# CANADIAN MENTAL HEALTH RESOURCES

Suicide Prevention Service (Canada) - 833-456-4566 or text 45645

Hope for Wellness Helpline - Canada - 1-855-242-3310 · www.HopeforWellness.ca

# **Wellness Together Canada**

www.WellnessTogether.ca · text WELLNESS to 741741 for immediate crisis support

#### LIVER CANCER INFORMATION AND SUPPORT

Cancer Support Community - 1-888-793-9355 · https://CancerSupportCommunity.org

American Cancer Society - 800-227-2345 · https://Cancer.org

**Global Liver Institute -** 800-845-5910 https://GlobalLiver.org/

American Liver Foundation - 1-800-465-4837 https://LiverFoundation.org/

Blue Faery - https://BlueFaery.org/

American Transplant Foundation - https://AmericanTransplantFoundation.org/

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**Open to Options**® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer**® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more:

www.CancerSupportCommunity.org/Find-Location-Near-You Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

This publication is available to download and print yourself at <a href="https://www.CancerSupportCommunity.org/Liver-Cancer">www.CancerSupportCommunity.org/Liver-Cancer</a>
For print copies of this publication or other information about coping with cancer, visit <a href="https://www.CancerSupportCommunity.org">Orders.CancerSupportCommunity.org</a>

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This publication was made possible through generous support from:

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