

Fibrolamellar cancer

What is fibrolamellar cancer?

Fibrolamellar cancer is a rare type of liver cancer. Fewer than 1 in 100 liver cancers are this type. It's most often diagnosed in teenagers and young adults.

It is a cancer of liver cells. Cells called hepatocytes start to multiply and grow more than they should.

The liver is the largest organ in the body. It has over 500 different functions, including:

- helping to digest and store nutrients from your diet
- helping blood to clot
- making bile and processing toxins, including alcohol and drugs

Fibrolamellar cancer is thought to be a rare subtype of hepatocellular liver cancer (HCC). So you may hear it called fibrolamellar hepatocellular cancer.

Symptoms

Early fibrolamellar cancer may not cause any symptoms. If you do have symptoms, they may be vague. You may:

- have tummy (abdominal) pain or swelling
- lose weight without trying
- lose your appetite
- feel sick
- feel generally unwell and lacking in energy

All these symptoms can be caused by other conditions – it's important to see your GP to find out what's causing them.



Risks and causes

As fibrolamellar cancer is rare, there are no official figures of how many cases there are. Experts estimate fewer than 20 cases in the UK each year. It's most often diagnosed in people in their teens or twenties. There are also some cases in people over 70. It seems to be equally common in men and women.

We don't know what causes fibrolamellar cancers – there are no known risk factors. Most cases of HCC are related to serious scarring of the liver (cirrhosis) from other liver diseases. But fibrolamellar cancer is usually diagnosed in younger people with no history of liver disease.

Tests

To start with, most people see their GP. They may do some blood tests and will examine you. If they feel a lump in your liver, or your blood tests are abnormal, your GP will refer you to a specialist. At the hospital, you may have:

- more blood tests
- an ultrasound, CT and MRI scan

Your specialist may be able to diagnose fibrolamellar cancer from a scan. But sometimes they need a tissue sample (biopsy). To get this, they usually numb the area over the liver and put a thin needle in through the skin. The biopsy will be examined for signs of cancer, which can take a week or so.

After your tests, a group of specialists called a multi-disciplinary team (MDT) will meet to look at the results of your tests and decide on the best course of treatment for you.

Stages

The stage of a cancer means how far it's grown and whether it has spread. Doctors decide on treatment according to stage. There are different staging systems. For fibrolamellar cancers, doctors use the TNM staging system. TNM stands for:

- **T**umour – the number and size of liver tumours
- **N**ode – whether there are cancer cells in any nearby lymph nodes (glands)
- **M**etastasis – whether the cancer has spread to another part of the body (metastasis means cancer spread)

There are 4 main stages.

- **Stage 1** – there is a single small tumour in the liver
- **Stage 2** – there are several small tumours, or one that has started to grow into nearby blood vessels
- **Stage 3** – the cancer has started to grow into a major blood vessel or body organs next to the liver
- **Stage 4** – the cancer has spread to lymph nodes or to another part of the body

Treatment

Your treatment depends on whether it's possible to completely remove the cancer with surgery. Even though fibrolamellar cancer is often quite advanced when it's found, surgery to remove it is possible in 3 out of 4 people diagnosed.

If your cancer can't be removed, or comes back, there are other types of treatment available. Your doctor will talk through the options with you and your family, so you can decide together what's best for you.

Surgery

If the cancer is only in one part (lobe) of your liver, you will have that part removed (**a liver resection**). This is the treatment most people have.

The liver is the only body organ that can grow back. As people with fibrolamellar cancer usually have healthy livers, it's possible to remove quite a large amount with no long-term ill effects.

If the cancer is too widespread in the liver, your specialist may suggest a **liver transplant**.

Both resection and transplant are major surgery. Depending on the exact treatment you have, it could take 6 months to a year to recover.

If your cancer comes back in the liver after surgery, you may be able to have more surgery to remove it. If not, you'll have one of the treatments below.

Drug treatment

If you can't have surgery, or your cancer comes back, you may have treatment with chemotherapy or targeted cancer drugs.

- Chemotherapy kills cells that are dividing (which cancer cells do more often than normal cells).
- Targeted therapies attack the genetic differences that cancer cells have – stopping them from multiplying or stopping them growing blood vessels to bring food and oxygen to the cancer.

There is no standard drug treatment for fibrolamellar cancer. Clinical trials are looking into potential new treatments. If you are interested in joining a clinical trial, speak to your specialist.

Other treatments

Sometimes doctors use external radiotherapy to control cancer symptoms or to treat cancer that's spread to another part of the body. Your doctor may also use a highly targeted type of this treatment (stereotactic radiotherapy) to treat a small tumour in the liver.

You may also have medicines to help control any symptoms you have, such as sickness.

Check-ups

After your treatment finishes you'll have check-ups, or follow up appointments.

After surgery, you usually see your doctor after 6 weeks, then 3 monthly.

If you've had a liver transplant, you'll see your surgeon weekly, then fortnightly, then monthly. If all's well, it'll then be 3 monthly.

If you're having any drug treatment, you usually see the doctor every few weeks. How often depends on the treatment you're having. After treatment you may see them every 3 months.

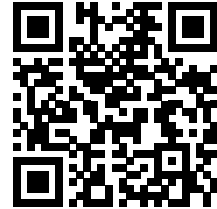
You may have regular blood tests or scans. If you start to feel more unwell, or have a new symptom or side effect, contact your hospital. You don't have to wait until your next appointment.

Getting help and support

A diagnosis of cancer can be extremely worrying and you may have a lot of questions. Talk to your doctor about anything you don't understand. You can also call the British Liver Trust's helpline on **0800 652 7330** to speak with a liver nurse specialist, or email the helpline at helpline@britishlivertrust.org.uk

You can read more detailed information about tests and treatment, and advice on living with liver cancer, on our website.

Scan the QR code with your phone or visit www.livercanceruk.org



The organisations below can also provide further information and support:

The Fibrolamellar Cancer Foundation

This US non-profit organisation leads and supports the largest cancer research network focused on fibrolamellar. They bring patients together through annual meetings and social media communications.

www.fibrofoundation.org

Instagram #fibrofoundation Twitter @FibroFoundation

Fibrolamellars of the World Unite

Facebook support group for patients and families affected by fibrolamellar. It is a closed private group, run independently, and is not moderated by healthcare professionals. www.facebook.com/groups/fibrolamellar

Fibrolamellar UK

UK Facebook support group, run by a patient. It is a closed private group and is not moderated by healthcare professionals.

www.facebook.com/groups/145175763267160/

Fibrolamellar Registry

US website run by patients. Patients share their medical information confidentially, then it's collated and shared with doctors and scientists to support scientific research. www.fibroregistry.org

Macmillan Cancer Support

Macmillan provides emotional, financial, and physical support to anyone affected by cancer. www.macmillan.org.uk



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