South West Liver Unit

NHS
University Hospitals Plymouth
NHS Trust

Patient Information Leaflet

Hepatocellular Carcinoma Surveillance

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This leaflet is for people with a diagnosis of stable (compensated) liver cirrhosis (scarring of the liver) who are being offered a primary liver tumour surveillance programme. It can also be called Hepatoma/Hepatocellular (HCC) surveillance.

Why do I need surveillance?

Having liver cirrhosis puts you at risk of developing primary liver cancer. This is a cancer that starts in the liver. These cancerous liver tumours are called Hepatocellular carcinoma (HCC) or hepatomas. Research from around the world has shown that the risk of HCC can be between 1-8% (1 to 8 people out of 100) depending on the cause of your liver disease. Please do not hesitate to ask your doctor or nurse if you would like more information about this.

The aim of the surveillance programme is to detect HCC in your liver at an early stage so that we can offer you effective treatment or monitor the growth of the tumour more closely.

What is hepatocellular carcinoma surveillance?

All patients who are felt to be suitable to be in the HCC surveillance programme will be offered liver ultrasound and review of specialist blood tests.

You will be offered an ultrasound of your liver and blood tests twice a year. However, you will be seen in clinic once a year. At this clinic appointment you will have a review of your tests, medications and a discussion regarding any lifestyle changes that may reduce liver disease progression.

After your next six monthly blood tests and ultrasound you will not need to come to a clinic appointment. Your blood tests and ultrasound results will be looked at by a member of the hepatology team. We will send you a letter to inform you and your GP of your results.

As part of your HCC surveillance we will also ensure that you have had some other investigations. These include:

Oesophageal Gastro-Duodenoscopy (OGD) this is a camera test that is passed through your mouth down into your stomach and first part of your bowel. This is to look for any swollen blood vessels which are called varices. These can be a sign of liver disease progression

Bone Density Scan (DEXA Scan) this is an x-ray that allows us to assess the thickness of your bones. People with cirrhosis have an increased risk of thinning of the bones (osteopenia / osteoporosis). This means you are at risk of breaking bones more easily. We will do this if you have never had one or if previous scans showed:
Osteopenia (weakened bones) and the DEXA scan will be repeated every 3-5 years
Osteoporosis (thin bones) and the DEXA scan will be repeated every 2-3 years

Vitamin D level people who have cirrhosis are at an increased risk of having a low vitamin D level. Low vitamin D levels can cause bone thinning which can increase your risk of a bone fracture. We would recommend that you are treated with vitamin D replacement according to our local guidelines.

Medications: It is very useful if you can bring an up-to-date list of your medications including any that you buy from the chemist or from the internet. This helps us to ensure that you are not on any medications that could be harmful to your liver or that you are taking medications that you no longer need

Height, Weight and Body Mass Index: This is important information for us to know as we will discuss your diet and exercise abilities when we see you in clinic

Performance / Frailty status: You will be asked how you perform certain tasks. This helps us to understand more about your fitness for possible treatment should we find a HCC on your investigations

People are entered into HCC surveillance if

- They have been diagnosed with cirrhosis. This will have been diagnosed by using ultrasound, liver biopsy, fibroscan or by the nature of your symptoms.
- They have no complications relating to cirrhosis such as ascites (fluid in the abdomen). You may hear this described as compensated cirrhosis.
- They have been diagnosed with Hepatitis B Virus (HBV) without evidence of cirrhosis.
- They have been treated for Hepatitis C and had a high fibroscan (liver stiffness) measurement.
- They have fibrosis (scarring) of the liver that is not quite cirrhosis but the hepatology team feel that HCC surveillance is appropriate as they are at risk of progressing to cirrhosis.

There are several reasons why surveillance is no longer suitable.

- If your liver disease becomes more advanced. You may hear this called decompensated liver disease, when you have problems related to your cirrhosis such as developing fluid on your abdomen (ascites), have confusion relating to your liver disease (hepatic encephalopathy) or bleeding from blood vessels in your oesophagus (gullet).
- If you have other health conditions that would mean we cannot offer any of the treatments for HCC such as severe heart failure or chronic obstructive pulmonary disease.
- If you have increasing frailty. We assess patients' clinical frailty score and people with increasing frailty where treatment of HCC is deemed too high risk would no longer be eligible for HCC surveillance.
- If you have had improvement in your liver condition after review with the hepatology team.
- If you decide you do not wish to be included in the programme, we would discuss this within our hepatology team and write to your GP.
- If you are identified as no longer suitable for HCC surveillance. It will have been reviewed in the Hepatology MDT and the outcome of this will be discussed with you.

How effective is this surveillance programme in identifying HCC?

Combining the ultrasound and blood test increases the chances of detecting small HCC's. As with all test there are limitations and there is chance of missing very small tumours. The majority of HCC are slow growing and the interval of 6 months has been found to be sensitive enough in detecting any tumours at an early stage. Sometimes if we detect a very small abnormality within the liver we will repeat the ultrasound after 4 months.

However, not all HCC act in the same way, they have different "tumour biology". This means that some may grow faster than others. Sometimes what can be seen on an ultrasound examination can be limited. This can occur if you are overweight as the ultrasound cannot travel through the fatty layers. Some people will have very nodular livers due to cirrhosis. This means that as the liver has developed fibrosis or "scar tissue", the liver tissue has grown in a nodular or lumpy way. In these situations it can be difficult to see the whole liver or 'pick out' a small tumour.

If this is found to be the case in you, then the limitations of the surveillance programme will be discussed with you further in clinic.

What are the risks of being in a HCC screening programme?

Ultrasound is a safe, painless procedure. You will be asked not to eat before the ultrasound to provide the best pictures of the liver and surrounding organs and blood vessels. The blood tests will be done by doctors, nurses or phlebotomists.

What will happen if an ultrasound or blood test is abnormal?

If the ultrasound shows a possible tumour then the person doing the ultrasound will alert the doctor or nurse who requested the test. Your scan and blood tests will be urgently discussed in a specialist meeting. Following this, you are likely to be asked to come in for further radiology scans of your liver, usually a CT (Computerised Tomography) or MRI (Magnetic Resonance Imaging) scan. The doctor or nurse will also discuss this with you either in clinic or over the phone. Once further scans are done you will be seen again in hepatology clinic to discuss the results and plan appropriate treatment with you.

Frequently the MRI or CT scans do not show any evidence of HCC. The area that looked abnormal on ultrasound may be found to be a ‘cirrhosis nodule’ or regenerative nodule and we will discuss continuing with HCC surveillance. After this, the interval of screening (often going to 3 monthly) or radiology test used (for example, CT or MRI) may change. We will discuss this with you, if this is the case.

Any further information or queries

Please do not hesitate to answer as many questions as you wish from the team looking after you.

You can contact the Hepatology Specialist Nurses via their secretary on:
01752 439002

Our Website has helpful links: www.swlu.uk or join our facebook page: South West Liver Unit.

This chart may help you calculate the number of units of alcohol consumed in different alcoholic drinks.

No more than 14 units per week is recommended for most people.

Patients with liver cirrhosis are recommended to drink no alcohol.

Further information can be found here:

https://www.nhs.uk/LiveWell/Alcohol/Pages/Alcoholhome.aspx

Lifestyle recommendations for people with fatty liver disease

Lifestyle recommendations	Specifically incorporate	Speciaifally avoid
Sustained weight loss 5-10%	Water	Avoid sugary drinks
Calorie restriction	Portion control; 1200-1500 kcal daily for weight <115 kg 1500-1800 kcal daily for weight >115 kg	Avoid ‘going large’ avoid late night eating
Limit alcohol	<14 units per week	Too much alcohol > 14 units / week
Get sufficient sleep		Avoid caffeine at night to get a good nights sleep
Increase physical activity	Wear / down load on your smartphone a pedometer, aiming for 10,000 steps / day	Sedentary lifestyle
Avoid saturated and trans fats	Olive oil, nuts, avocado, oily fish (tuna, mackerel, sardines)	Fast food, fried food
Low carbohydrate diet	3-5 portions of vegetables and fruit 2-4 servings / day	Simple carbohydrates with fructose corn syrup

Your notes:

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This leaflet is available in large print and other formats and languages.
Contact: Administrator
Tel: 01752 431320

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