

A guide to understanding
advanced liver disease

Information for
patients and carers
about general health
and wellness





Introduction

Welcome to your guide to understanding advanced liver disease and general health and wellness. Throughout this guide, any unusual terms are highlighted in bold and explained at the end of this leaflet in the glossary. If you have any questions, remember to ask your doctor or nurse at your next appointment. We hope you find it informative and useful.

There are five other booklets available in this series that cover a range of topics, including **hepatic encephalopathy**, **varices** and **variceal bleeding**, **ascites**, **hepatocellular carcinoma** and nutrition. If any of these interest you, be sure to ask your doctor about them.

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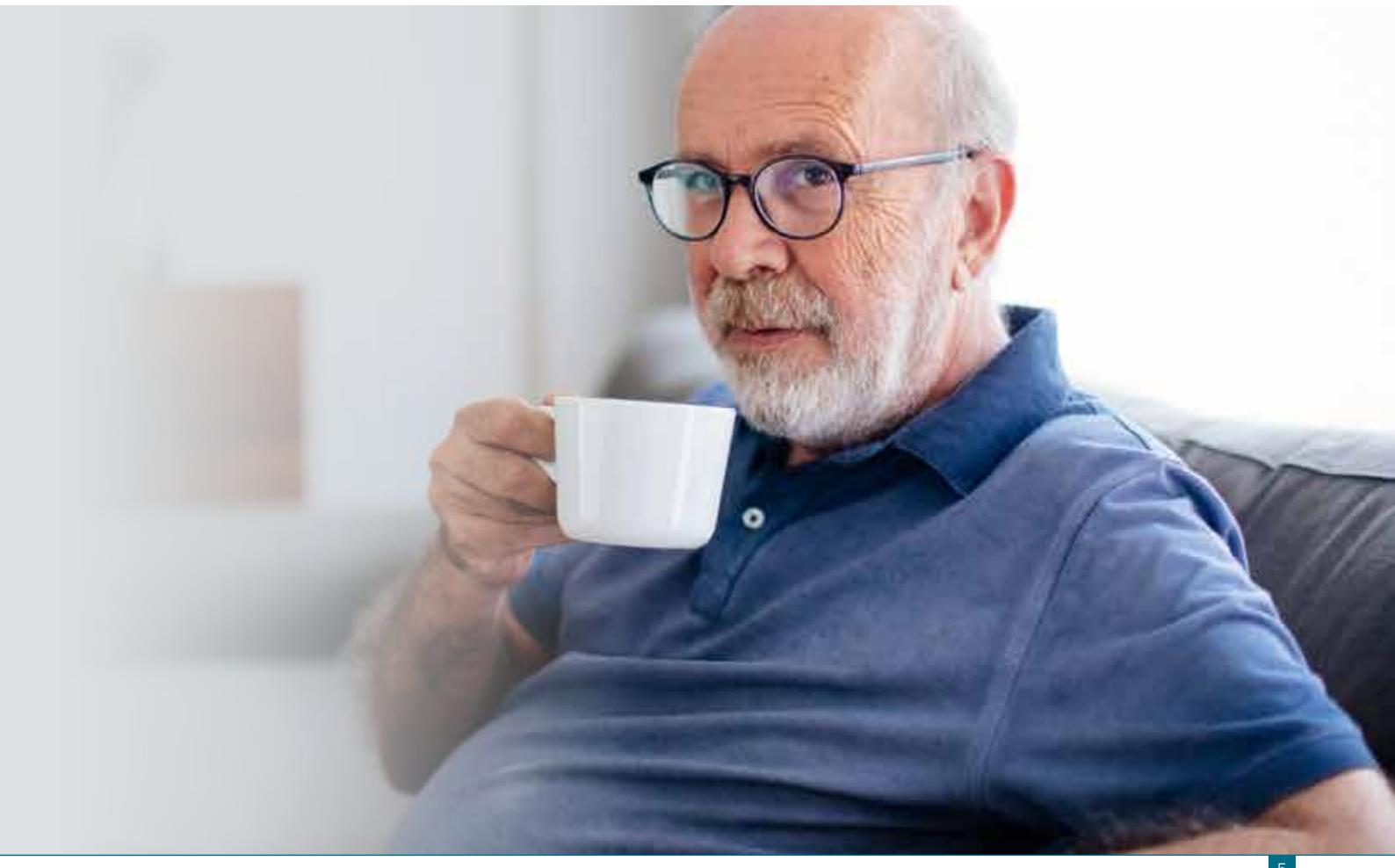
What is liver cirrhosis?

When a healthy liver gets injured by a virus, a toxin like alcohol or another specific liver disease, it repairs itself by replacing damaged cells with new ones. This is usually an efficient process but, when too much damage occurs and/or lasts a number of years, some of this repair work can leave scars. This is known as '**cirrhosis**'. At this point, if care is taken, the liver can usually cope with the damage and maintain its important functions. During this period, which can last years, there can be very few symptoms or even none at all.

In advanced liver disease, the scarring can become so great that the liver can no longer repair itself or function properly.

This can cause associated conditions like hepatic encephalopathy, ascites, variceal bleeds or hepatocellular carcinoma. In this booklet, we focus on general health and wellness.

Advanced liver disease and cirrhosis can have several causes including long term alcohol abuse, viral infection such as **hepatitis B or C**, metabolic diseases such as **non-alcoholic related fatty liver disease (NAFLD)**, or other conditions such as autoimmune hepatitis.



What can I do to look after my health?

Knowing that your health is at risk can be worrying. Being well informed and following advice from professionals should give you the best chance of successfully living with your condition. It's also important to remember, you are not alone.

If you would like to find out more about others in a similar situation to you, please see the patient support group information at the back of this leaflet

Despite having a serious condition, looking after yourself as much as possible can still provide you with some real benefits. It is important to try and maintain as healthy and normal a life as possible. Mostly, that means taking all your medicine just as your doctor and medical team has advised you to, eating and drinking well, avoiding alcohol and cigarettes, staying active and trying to prevent additional health problems like flu or pneumonia. It's a lot to think about but reading this leaflet can help to keep it simple.



Taking medication as prescribed

This is really important. Your condition is very serious and complicated and it is often the case that you will be suffering from other illnesses at the same time. You may have many different medications to take at various times throughout the day. Try and get to know their names and what each of them are for. They will all come with their own individual guidance, so it's important to try and stay on top of things. Keep a diary or timetable if you think it could help.

You'll need to find a way to manage this timetable to fit in with your busy life. If you have a smart phone, put in regular reminders of what to take and when. You could also ask a friend or family member to remind you about your medicine, or keep it somewhere visible so you will be reminded at the right time. For example, next to your toothbrush if you want to relate it to your morning/night-time regime.

Be sure to keep taking your medication for as long as you have been instructed, even if you are feeling better or the symptoms seem to be easing.

If you are thinking of taking other non-prescription medicine, like herbal or traditional medicine, make sure you let your doctor know before you do this. Even complimentary medications that claim to be 'good for liver health' can be dangerous for people with liver disease.

Eating and drinking well

Getting your diet right is really important.

The nature of your illness means that your body has difficulty getting the energy and nutrition it needs from a normal diet.

Because your body can struggle to absorb the nutrition from food, it helps to eat or drink foods that are highly nutritious like vegetables, fruit and smoothies. Talk to your doctor or dietician about creating a diet that is simple to follow and specifically designed for your particular needs.



Alcohol and smoking

Drinking even a small amount of alcohol with your condition can be very dangerous.

This is even the case if your cirrhosis wasn't caused by alcohol. Drinking alcohol now will only cause further damage to the liver as well as leading to other negative effects on your health.

If you need help to stop drinking, there are various options you might consider. The best place to start is by talking to your doctor to see what they advise. There are motivational therapies that have been shown to change drinking behaviour and there are also prescription medicines that can help support these motivational therapies. In addition, there are groups for people going through the

same challenges and getting involved in them could provide you with the help you need.

If your drinking habit is severe, and your dependency on alcohol is very strong, it may be that time in hospital will be needed, as suddenly cutting out alcohol can cause severe complications too.

Smoking is also something that should be avoided as research suggests that smoking can cause extra scarring and inflammation to an already fragile liver. If you need help quitting smoking, the first step is talking to your doctor as they may be able to suggest suitable treatments or give you useful advice. Combining medication with help and support from a stop smoking network has been shown to produce the best results.

If a liver transplant is a possible option for you, it is really important to remember that not drinking or smoking will make you a more likely candidate. You are not allowed a transplant unless you have been abstinent from alcohol for at least 6 months.



[For support in giving up either alcohol or cigarettes, please see the support group information at the back of this leaflet.]

Staying active

Sometimes, being active will be the last thing you want to do. After all, tiredness is one of the symptoms of your condition and your doctor may well have talked about the need for rest. However, when you are not resting, it is really important to stay as active as possible.

This is because, when we are active, our heart and lungs work harder, and as a result, we carry more oxygen in our blood. This oxygen eventually gets transported to the liver, helping it to function better.

Being active also helps us to build up our physical strength and resistance so we can keep dangerous infections away.

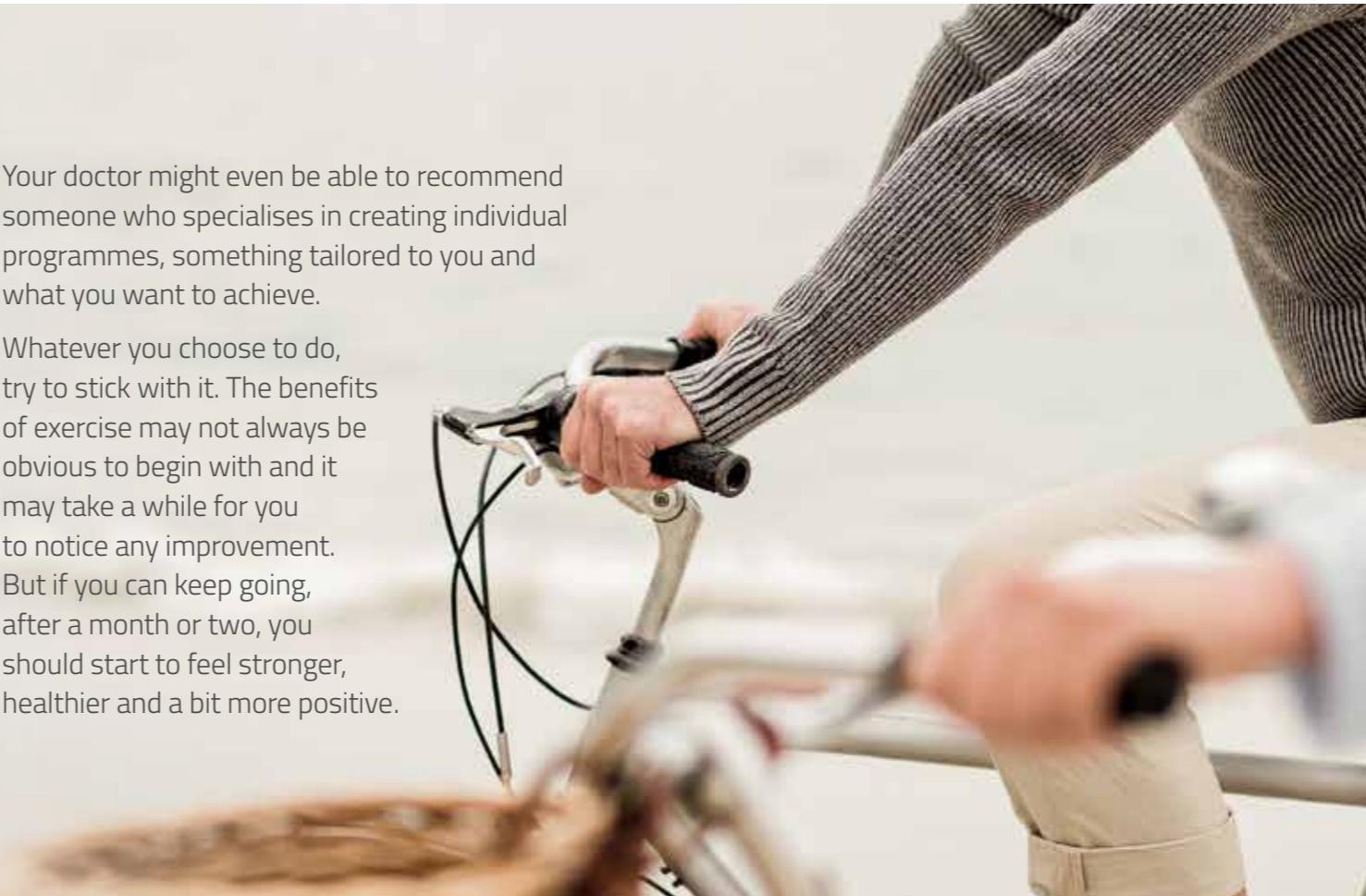
Another issue with cirrhosis is that your body can struggle to maintain its usual muscle mass, because with your condition, it's difficult to absorb proteins. Exercising your muscles can help to combat this.

The type of physical activities that are good for you come in many forms. From simply being active around the house, to being out and about walking, cycling, even playing sports. They can all help you become healthier and may even improve your chances of survival.¹

If it has been some time since you have really been active, or exercised, it is important that you begin at a level that is right for you. This might just be a light walk of 10-15 minutes in the beginning, some light swimming, some gentle press ups against a wall or using tins of food as weights.

Your doctor might even be able to recommend someone who specialises in creating individual programmes, something tailored to you and what you want to achieve.

Whatever you choose to do, try to stick with it. The benefits of exercise may not always be obvious to begin with and it may take a while for you to notice any improvement. But if you can keep going, after a month or two, you should start to feel stronger, healthier and a bit more positive.



Preventing other illnesses

Because of your condition, you will find that your general level of **immunity** to other illnesses is also a bit low. You will need to be extra careful to avoid certain people or places where you might catch things like colds or the flu.

You should talk to your doctor about vaccines for flu, pneumonia or other viruses, particularly in the winter.

Also, if you are travelling abroad, make sure you have any vaccinations for that destination well before you travel.



Stress or depression

Having cirrhosis can put a lot of mental pressure on you, making you more likely to suffer from stress or depression.

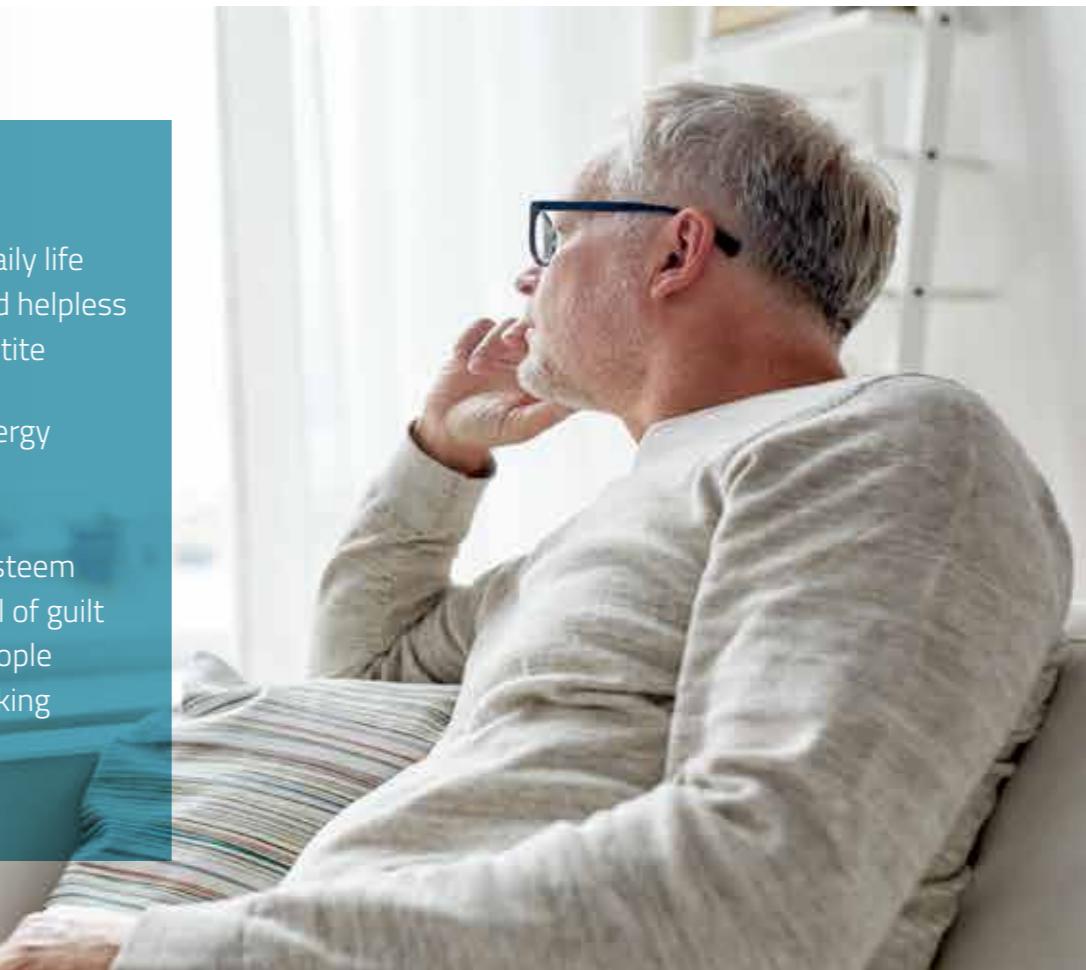
Confusingly, some of the symptoms that can come with stress or depression are the same as those you might have because of your condition. But take a look at the list of symptoms to the right, and see if this sounds like something you are experiencing. If it does, talk to your doctor just to be sure as there are treatment options available and they may be able to help.

Common symptoms of stress:

- Generally low on energy
- Headaches
- Trouble sleeping
- Tight-feeling in the chest
- Rapid heartbeat
- Upset stomach, including: diarrhoea, constipation or nausea
- Aches and pains
- Tightness in the muscles
- Loss of sexual desire

Common symptoms of depression:

- Loss of interest in daily life
- Feeling hopeless and helpless
- Change in your appetite or weight
- Generally low on energy
- Aches and pains
- Trouble sleeping
- Low mood or self-esteem
- Feeling tearful or full of guilt
- Irritated by other people
- Having difficulty making decisions
- Thoughts of suicide



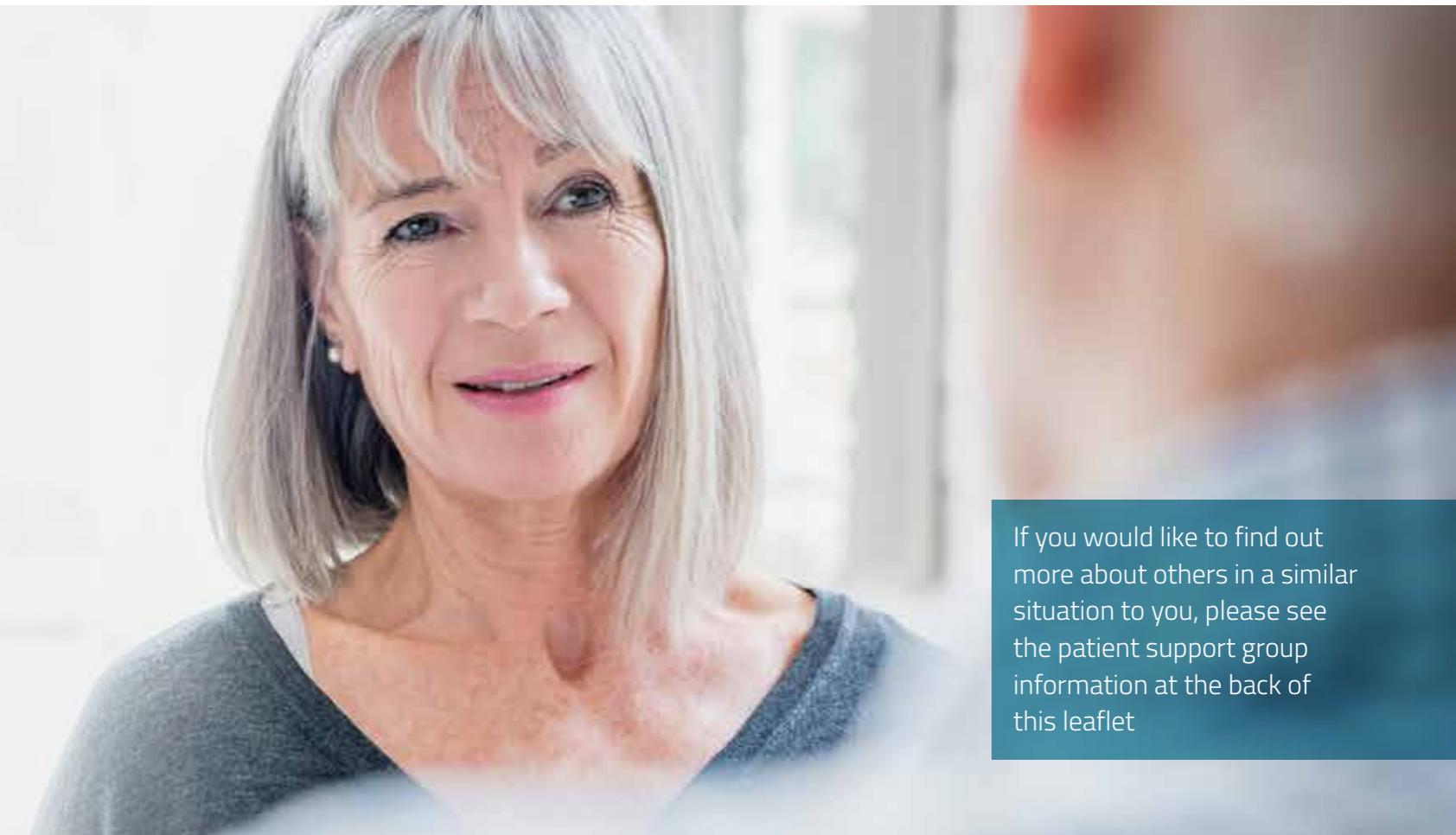
What more can I do for my health?

There is a lot to think about in terms of your health when you have cirrhosis. To help you avoid feeling overwhelmed, here's a list of top-tips that can help you focus on the most important things and keep it simple and achievable:

- Always take your medicine as instructed
- Eat a well-balanced diet with plenty of fresh fruit and vegetables
- Avoid processed food, fast food and ready meals
- Avoid cigarettes and alcohol
- Make sure you get a good balance of work, rest and exercise

- Have your vaccinations for flu and pneumonia
- Get help if you notice symptoms of stress, anxiety or depression

Of course, you might need emotional support too, from family or friends or other people going through the same experience – talk to your doctor about special groups you may be able to join or places you could get specialist advice.



If you would like to find out more about others in a similar situation to you, please see the patient support group information at the back of this leaflet

Glossary

Ascites: A build-up of fluid in the abdomen.

Cirrhosis: Where healthy liver cells become damaged and are replaced with scar tissue.

Hepatic encephalopathy: A change in the brain that can occur in patients with advanced liver disease due to high levels of toxins in the brain.

Hepatitis B and C: Two conditions that cause inflammation of the liver due to viral infection.

Hepatocellular carcinoma: A type of liver cancer that is common in people with cirrhosis.

Immunity: This is a measure of how well your body is able to defend itself against illnesses.

Liver: The largest organ inside the human body. Among other things, it is responsible

for removing toxins from our blood, producing certain molecules like hormones and storing and releasing energy from food.

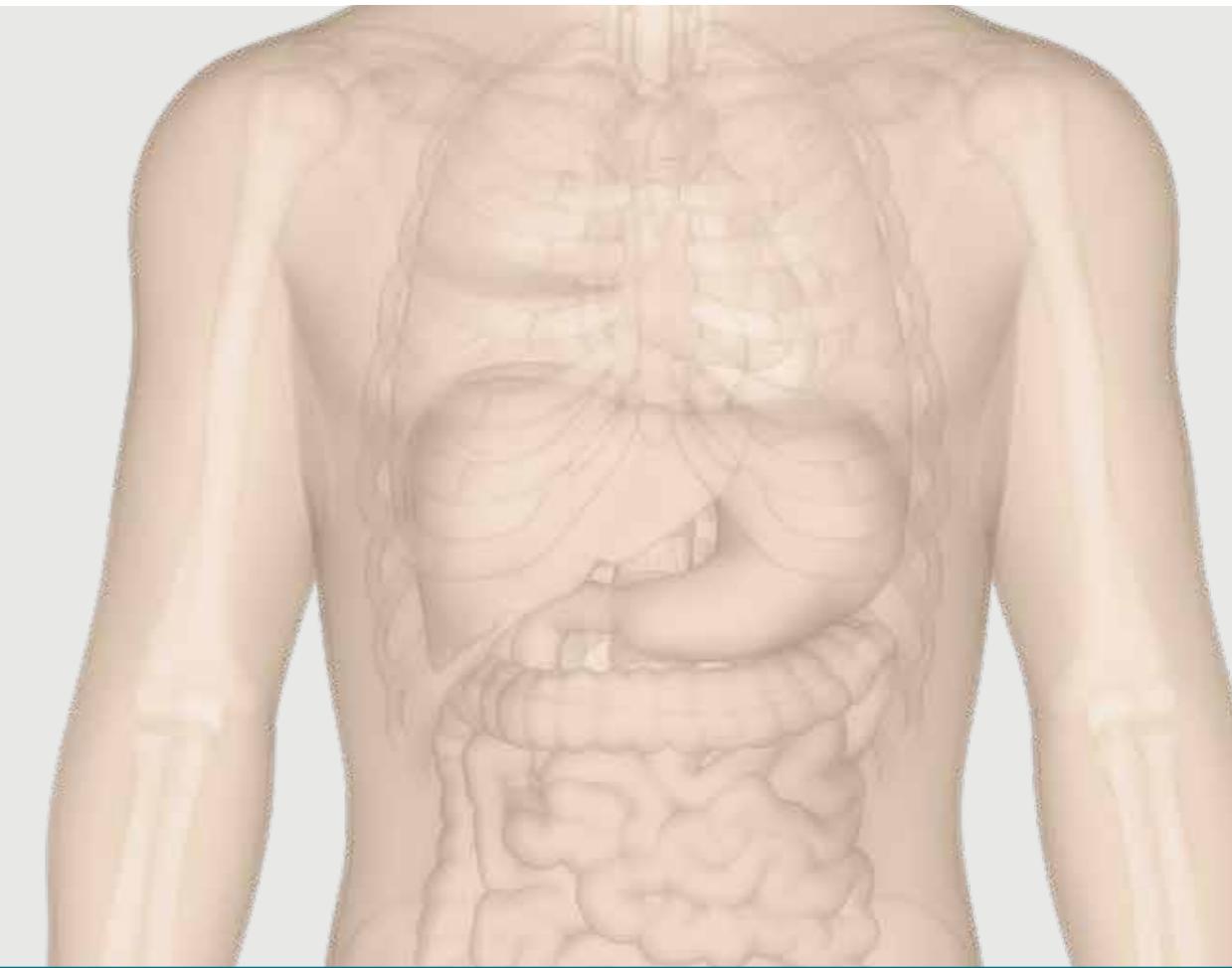
Non-alcohol related fatty liver disease (NAFLD):

NAFLD is when you get a build-up of fat in your liver.

Toxins: Harmful chemicals that enter the body through our normal daily activities such as eating, drinking and breathing. A healthy liver helps to remove these toxins from the body.

Variceal bleed: When small veins (known as varices) burst, causing serious bleeding.

Varices: Small veins that have become larger, twisted and swollen due to blood being redirected to them.



Reporting of side effects due to prescribed medicines

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard.

By reporting side effects, you can help provide more information on the safety of this medicine.

Reference:

1. Mukerji AN, et al. Improving Survival in Decompensated Cirrhosis. *Int J Hepatol* 2012; 2012: 318627. doi: 10.1155/2012/318627.

Disclaimer:

The images are being used for illustrative purposes only. Any persons depicted are models.

Primary reading:

- <http://www.liverpatientpassport.com/mobile/index.html#p=2>
- <https://www.britishlivertrust.org.uk/liver-information/liver-conditions/cirrhosis/>
- <https://www.hepatitis.va.gov/patient/complications/cirrhosis/care-of-liver.asp>
- <https://www.webmd.com/a-to-z-guides/tc/variceal-bleeding-as-a-complication-of-cirrhosis-topic-overview>

Support groups:

European Liver Patients' Association:
<https://www.elpa.eu>



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