

Life after liver transplant



Fighting liver disease

Life after liver transplant

The British Liver Trust works to:

- support people with all kinds of liver disease
- improve knowledge and understanding of the liver and related health issues
- encourage and fund research into new treatments
- lobby for better services.

All our publications are reviewed by medical specialists and people living with liver disease. Our website provides information on all forms of adult liver disease and our Helpline gives advice and support on general and medical enquiries. Call us on **0800 652 7330** or visit **www.britishlivertrust.org.uk**

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The liver

Your liver is your body's 'factory' carrying out hundreds of jobs that are vital to life. It is very tough and able to continue to function when most of it is damaged. It can also repair itself – even renewing large sections.

Your liver has around 500 different functions.

Importantly it:

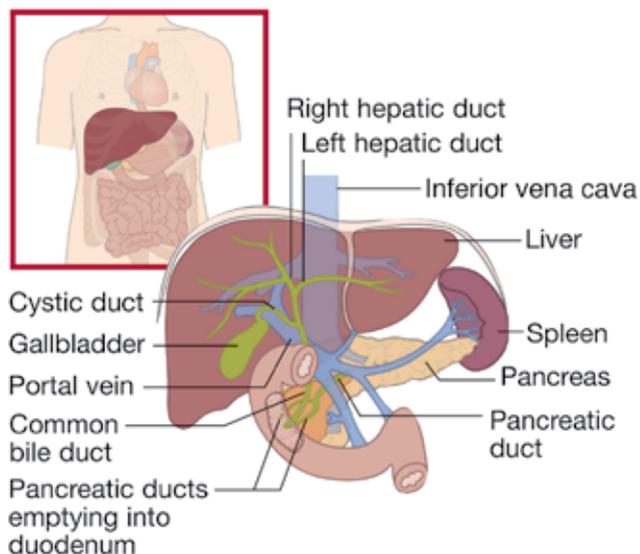
- fights infections and disease
- destroys and deals with poisons and drugs
- filters and cleans the blood
- controls the amount of cholesterol
- produces and maintains the balance of hormones
- produces chemicals – enzymes and other proteins – responsible for most of the chemical reactions in the body, for example, blood clotting and repairing tissue
- processes food once it has been digested
- produces bile to help break down food in the gut
- stores energy that can be used rapidly when the body needs it most
- stores sugars, vitamins and minerals, including iron
- repairs damage and renews itself.

How liver disease develops

Liver damage develops over time. Any inflammation of the liver is known as hepatitis, whether its cause is viral or not. A sudden inflammation of the liver is known as acute hepatitis. Where inflammation of the liver lasts longer than six months the condition is known as chronic hepatitis.

Fibrosis is where scar tissue is formed in the inflamed liver. Fibrosis can take a variable time to develop. Although scar tissue is present the liver keeps on functioning quite well. Treating the cause of the inflammation may prevent the formation of further liver damage and may reverse some or all of the scarring.

Cirrhosis is where inflammation and fibrosis has spread throughout the liver and disrupts the shape and function of the liver. With cirrhosis, the scarring is more widespread and can show up on an



ultrasound scan. Even at this stage, people can have no signs or symptoms of liver disease. Where the working capacity of liver cells has been badly impaired and they are unable to repair or renew the liver, permanent damage occurs.

This permanent cell damage can lead to liver failure or liver cancer. All the chemicals and waste products that the liver has to deal with build up in the body. The liver is now so damaged that the whole body becomes poisoned by the waste products and this stage is known as end stage liver disease. In the final stages of liver disease the building up of waste products affects many organs. This is known as multiple organ failure. Where many organs are affected, death is likely to follow.

Looking ahead

Today, the number of people surviving liver transplantation is higher than ever before and the vast majority now go on to lead an active life. This publication is written for people and their families who have received a liver transplant, or who may be receiving a new liver in the future. It is a reference point for information you might need in the months and years to come, to help you live life after a liver transplant.

Transplantation is still very complex and remains a treatment rather than a cure for your condition. Because of this it is not unusual for some people to find themselves readmitted to hospital during the first year. Complications following transplantation can be caused by infections, recurrent disease such as primary biliary cirrhosis (PBC) or cancer and problems in other parts of the body that can take several years or decades to unfold.

The powerful drugs that play such a big part in helping people survive and recover from transplantation can pose their own problems. Many of these can have side effects that affect some people more than others.

For some people, staying away from alcohol remains a major physical, social and/or psychological challenge for them to overcome.

These factors, combined with the fact the liver is such a complex and vital organ, mean that liver transplantation – from assessment to the transplant itself and your recovery period – is a unique procedure that requires a wide range of specialist health professionals to help you back to as normal a life as possible.

Although you will be required to attend follow-up clinics for the rest of your life, for most people these visits will become less regular as

they get better. Follow up is normally at your transplant centre in the first year and after this, all going well, it is possible for your care to be shared with your local GP. However, you can choose to be seen at your transplant centre indefinitely.

This publication is focused on the main complications that affect some people after liver transplantation. It looks at why these are thought to happen and the likely risk factors for them. If you do have problems, it is very likely you will need to keep in close contact with your transplant team and let them know when you feel something isn't right. In addition to specialist medical care that is in place to manage complications, transplant centres will have support services to help you with day-to-day things. These should include liaison staff to provide advice and support to help you if you are feeling anxious or down. Similarly, if your transplant was needed either wholly or partly because of alcohol or drug issues you will certainly benefit from speaking with a substance misuse specialist who should be available to help you if you're struggling.

There is useful advice in this publication about these things but you are encouraged to seek help from the professional services that are available to you in the first instance, including the information provided by your transplant centre. This is particularly important where you feel that some of the information appears confusing or even contradictory.

Immunosuppression

Although this leaflet looks mainly at possible complications following liver transplantation, it is useful to begin with immunosuppression, as any problems here will often have a bearing on the nature of your recovery.

Rejection

Your immune system has the job of keeping viruses, harmful bacteria and other organisms out of your body. Without medicines, your

immune system can see your new liver as something to be attacked. This is called 'rejection'. Some level of immune response is quite common and occurs in more than half of liver transplants, usually within five to ten days but possibly at any time.

Rejection following soon after surgery is called 'acute rejection'. It does not mean that you will lose your new liver but it is very important that doctors stop rejection as early as possible.

Rejection that occurs some time after transplantation is called chronic rejection. It is noticeable by a gradual loss of liver function over time, sometimes years.

To prevent rejection of the new liver, doctors will give you medication to make the immune system less aggressive. This is immunosuppression. You will need to take one or more of these anti-rejection drugs – called immunosuppressants – for the rest of your life.

What are the warning signs of rejection?

The main signs of rejection to look out for are:

- fever (38°C or over)
- flu-like symptoms such as chills, aches, fatigue and headaches
- pain or swelling in the abdomen
- nausea and vomiting
- breathlessness
- itching

If you experience any of these signs, contact your transplant team immediately. It is possible that you won't have clear symptoms, so it is essential for you to attend clinic as often as you are asked to allow staff to keep an eye on you for other signs of rejection.

Chronic liver rejection takes some time to happen and is more difficult to treat. Fortunately it affects very few people. There is medication to control chronic rejection, but if this does not work another transplant will be needed.

How does immunosuppression work?

To function effectively your immune system relies on certain types of white blood cells that are produced in your bone marrow and lymph glands. Known as T and B lymphocytes, these cells make antibodies that protect the body from invading infections. Immunosuppressant drugs reduce the production of T and B lymphocytes by interfering with the production of genetic material within the cells, known as DNA. This prevents the cells from dividing and multiplying.

With fewer white blood cells the immune system is weaker and less able to reject the transplanted organ.

What are the side effects of immunosuppression?

Having a weakened immune system also means that you pick up infections more easily. Immunosuppressants can also interfere with the production of other types of blood cells in the bone marrow. Having fewer red blood cells can lead to anaemia and a slow down in the production of platelets can cause problems with blood clotting. For this reason, doctors will check levels of all your blood cells during treatment.

Other possible side effects of immunosuppressants are:

- kidney damage (nephrotoxicity)
- high blood pressure (hypertension)
- an increase of blood fats (hyperlipidemia)
- insulin resistance (diabetes)
- bone thinning (osteoporosis), if long-term use of steroids is part of your treatment

Again, your transplant team will monitor the concentration of medications in your blood to help avoid or manage any complications.

Medications

The drugs most commonly given to prevent organ rejection are cyclosporin, tacrolimus, sirolimus, azathioprine, mycophenolate and prednisone. You may also take additional medication to manage some of the effects of these and to keep out infections.

Cyclosporin and tacrolimus are known as calcineurin inhibitors (CNIs). They are most commonly used and work by blocking calcineurin (a protein) that sets off the sequence of cell activity that gets the immune system into action. CNIs work very well and have greatly helped to improve the success rates for transplantation. Because some people cope less well with the side effects of these drugs, doctors may lower the dose or switch to the other anti-rejection drugs, each of which works slightly differently.

Another medicine used is called sirolimus. This is an effective immunosuppressant as it prevents the rapid multiplication of T-cells that the body produces when it senses an 'invader', and it is this reaction that causes rejection.

Azathioprine and mycophenolate are anti-proliferative immunosuppressants. These work through blocking the action of a compound which is required for making certain blood cells that regulate and trigger immune responses by the body against infection and foreign cells.

Prednisone is a type of steroid known as corticosteroid, which also weakens the immune system. Use of corticosteroids is gradually reduced and may be stopped after six months.

Each of the drugs used will have its benefits and drawbacks. To make them most effective doctors will prescribe them in certain combinations, known as regimens. Most transplant units use a triple regimen, based on a CNI (cyclosporin or tacrolimus), antiproliferative immunosuppressants (mycophenolate or azathioprine), and a corticosteroid (prednisolone).

Most immunosuppression drugs can be taken in capsule or tablet form while others must be given by injection into the blood stream (IV). Certain drugs, such as cyclosporin and tacrolimus, are never given together. There is more information about medicines on pages 14–15.

I've heard I can't drink grapefruit juice, is that true?

If you are taking tacrolimus then grapefruit or grapefruit juice can interfere with the absorption and effectiveness of the drug. If you really love grapefruit then make sure that you don't have any one hour before or after taking your tacrolimus. If you are worried, discuss it with the transplant coordinators at your transplant centre.

Your hospital should provide you with a medication card to record information about your medication, dosages and the times drugs were administered. When you are discharged from hospital, exact information about your medication should also be passed from the transplant unit to your GP. It is important your GP continues to prescribe at the same dose and formulation as the transplant team advises. Modified or slow release (MR) versions and non-MR versions (which are usually taken more frequently) should never be confused. You can help by checking your prescription and the tablets dispensed by the pharmacist against the dose and formulation advised by your transplant centre.

Side effects are most common in the first months following your transplant when the highest doses are given. Your doctors will carefully consider the most suitable regimen and correct dosage for you to help avoid or manage any side effects.

You may have begun to self-medicate while in hospital, but once you are at home, taking medications is your responsibility. It is important that you continue taking them as directed.

If you have difficulty organising your medications you may find it easier to use a medication dispenser. Talk to your hospital team or GP about the most sensible dispenser for you.

Ten tips for taking your medication:

1. Always take your medications at the time ordered and the exact dose prescribed
2. Learn the names of your medications and their side effects
3. Report all side effects to your transplant team
4. Do not change dosage without consulting your transplant doctor
5. Keep your medications in a dry place, out of sunlight and out of children's reach
6. Keep your medications in their original bottles or packaging
7. If you miss a dose, do not double the next dose. Tell your transplant team
8. Use a high factor sunscreen while in sunlight when taking anti-rejection medication
9. Carry a card or list with your medication details on it, particularly when travelling
10. Consult your transplant doctor or pharmacist before taking any over the counter medications.

Medical staff should be aware of side effects and what steps to take to reduce them. They should be aware of any underlying conditions you have and will closely monitor the effects of any medication given to you.

Side effects Note: <ul style="list-style-type: none"> • This is a list of potential side effects only • Not all side effects associated with these medications are experienced by all people • You should report all side effects to medical staff promptly 	Cyclosporin <i>(Neoral)</i> Calcineurin inhibitor (CNI) <ul style="list-style-type: none"> • capsules/tablets/liquid • don't take with grapefruit • never to be given with tacrolimus • do not take before blood tests at outpatient clinic 	Tacrolimus <i>(Prograf)</i> Calcineurin inhibitor (CNI) <ul style="list-style-type: none"> • capsules • don't take with grapefruit • never to be given with cyclosporin • do not take before blood tests at outpatient clinic
Kidney damage (nephrotoxicity)	●	●
High blood pressure (hypertension)	●	●
Headache	●	●
Tremors	●	●
Tingly hands and/or feet	●	●
Hyperglycaemia	●	●
Upset stomach or nausea	●	●
Increased hair growth	●	
Thickening of the gums	●	
Diarrhoea or constipation		●
Skin rash		●
Hair loss or thinning		●
Insomnia	●	●
Mental confusion	●	●
Sensitivity to sunlight	●	●
Gout	●	
Increase in cholesterol	●	
Impaired wound healing		
Acne		
Fluid retention		
Feelings of anxiety		
Lack of concentration		
Moodswings		
Weight gain		
Diabetes/increased blood sugar levels	●	●
Increased risk of infection		
Eye changes or visual problems		●
Softening of the bones		
Liver abnormality		
Mouth ulcers		
Aching joints		●
Increased appetite		
Thinning of the bones (osteoporosis)		
Fragile skin		

Sirolimus <i>(Rapamune)</i> Non-CNI immunosuppressant <ul style="list-style-type: none"> • tablets • don't take with grapefruit • must be taken at the same time every day • do not take before blood tests at outpatient clinic 	Azathioprine <i>(Imuran)</i> Antiproliferative immunosuppressant <ul style="list-style-type: none"> • initially by injection and continued in tablet form • tablets to be taken with food or glass of milk • never to be given with mycophenolate 	Mycophenolate <i>(CellCept)</i> Antiproliferative immunosuppressant <ul style="list-style-type: none"> • capsules and tablets • capsules and tablets to be swallowed whole with a glass of water • never to be given with azathioprine 	Prednisolone Corticosteroid <ul style="list-style-type: none"> • tablets • must be taken at the same time every day • always take with or after food (can irritate your stomach)
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You should still report side effects when they occur and ask for advice about managing them if you are unclear about the right steps to take.

During your follow-up visits, doctors will focus on liver function tests to check how well your new liver is working. For your part, it will not always be possible to control how things turn out but it is essential that you keep your clinic appointments. If you can't make an appointment, you may find that many problems can be sorted out by telephone.

Infection

Infections usually result from viruses that come to life after lying inactive (dormant) in your body or your new liver. Most of these infections would not harm anyone in good health but they can cause problems for people who are immunosuppressed.

Infections can be viral, bacterial or fungal. You are most likely to pick up an infection in the first few months after your transplant when doses of immunosuppressants are higher, but it is sensible for you to remain aware of infection risks in the long term.

Common infections following transplantation

Cytomegalovirus (CMV) is a type of herpes and a very common infection – more than 60% of all people are exposed to it at some point in their lives. CMV usually occurs during the first months after transplantation. Symptoms include headaches, nausea, sore throat, high temperature, fatigue and aching joints, although it is also possible not to have these signs. Doctors can diagnose the virus using a sensitive laboratory test such as the polymerase chain reaction test (PCR).

To treat the virus you will be given antiviral medication (ganciclovir) in either oral or intravenous form for several weeks. To protect against

CMV occurring (prophylactic treatment or 'prophylaxis'), doctors may prescribe antiviral drugs immediately after transplantation.

Herpes Simplex viruses (HSV) are two types of cold sore virus affecting the skin. Type 1 causes cold sores and blisters around the mouth, while type 2 causes genital herpes. After the first infection HSV lays dormant in the body until reactivated. Infection with HSV was more common after transplantation until prophylactic treatment with acyclovir (Zovirax) became routine.

HSV viruses are highly contagious and easily passed from close contact. If you have sore areas, keep them as clean and dry as possible; wash your hands with soap and water after touching them. Avoid kissing or having oral sex with someone who has a cold sore.

If you are prone to cold sores, keep acyclovir cream handy and use as soon as you think a sore is developing. There is no need to check with medical staff before using acyclovir.

Varicella-zoster virus (VZV) belongs to the same herpesvirus group as HSV and causes two fairly well-known diseases, chickenpox (varicella) and shingles (herpes zoster).

Chickenpox is a contagious disease more often seen in children. It usually appears as a rash or in small blisters. If you have been in contact with someone who has chickenpox, contact your transplant team immediately.

Shingles is caused by a much later reactivation of VZV in your body following chickenpox. There is a vaccine for shingles but it is unsuitable for immunosuppressed people as it contains live particles of the virus. Shingles appears as a rash or small water blisters, usually on the chest, back or hips. If you think you have this kind of rash, contact your transplant team.

Candida (yeast) is the most common fungal infection after liver transplantation. It usually starts in the mouth or throat but may also occur in the oesophagus (gullet), genital and urinary organs. An infection in the mouth, throat or vagina is called thrush. It appears as a patchy white coating on the tongue causing it to feel painful and tender. This can lead to difficulty in swallowing if it spreads to the throat. Vaginal infections usually cause a whitish discharge.

Fungal infections are treated with the drugs amphotericin or fluconazole (Fungilin), given either intravenously or as oral medication.

How do I know I have an infection?

A quick checklist of common signs to look for are:

- A raised body temperature or fever (pyrexia)
- tiredness or fatigue
- diarrhoea or vomiting
- redness or discharge around your operation scar, bile or tube site
- a cough or sore throat.

To determine the nature of the infection doctors may take blood, urine and mucus samples, as well as samples from areas outside of the body such as the operation scar and drainage site.

What can I do to prevent infection?

There are a number of fairly simple precautions you can take to stay healthy. In short, it is advisable for you to:

- avoid close contact with adults and children carrying infections – from the common cold to chicken pox
- have a flu vaccination each year
- have a pneumococcal vaccination for lifelong protection against the pneumococcus bacterium (it causes pneumonia, meningitis and other infections)
- avoid inhaling dust, particles or smoke

- keep good standards of hygiene – for example, washing your hands after going to the toilet or changing a baby's nappy
- brush your teeth after every meal and floss daily
- visit the dentist every 6 months and do not have dental work for the first six months after transplant (without seeking further advice from your transplant team)
- keep toenails and fingernails clean and trimmed
- thoroughly clean all cuts and grazes before applying a clean, dry dressing or plaster and keep an eye on them
- do not clean out the cat litter or bird cages, or go near animal excrement, without gloves
- for women, use only small tampons, change frequently and do not use overnight
- keep up-to-date with vaccines (see below).

What vaccines should I be given?

Routine vaccines such as those against flu and pneumococcal infection are important. However, you will be advised to avoid 'live' vaccines that contain tiny amounts of a particular disease. Live vaccines given in the UK include measles, mumps and rubella (MMR), TB (BCG vaccine), yellow fever, and the oral typhoid vaccine. It is also important that no-one in your household receives live vaccines either. Your doctor can advise on how you can protect yourself and order the necessary non-live vaccines for you and your household.

How can I avoid food poisoning infections?

Particularly during the first three months after your transplant, it is important that you avoid eating foods that may contain bacteria such as listeria, salmonella or E.coli. You might be more vulnerable to food poisoning and there can be problems whilst you are on high doses of anti-rejection drugs.

Foods that could contain listeria and other bacteria include:

- Unpasteurised milk
- Unpasteurised cheese and soft cheese such as feta, Brie, Camembert and blue vein cheese
- Pâté
- Live yoghurt
- Food that contains raw egg, such as home made mayonnaise
- Soft serve ice creams
- Refrigerated smoked seafood and fish
- Shellfish
- Unwashed salads
- Deli meats

Can I take antibiotics for my infection?

Most antibiotics are safe for you to take although some common antibiotics, such as clarithromycin and erythromycin, can interfere with cyclosporin and tacrolimus. Always ask your GP or medical staff whether the antibiotics you have been prescribed are safe to take with your immunosuppressant medication before starting your course.

Renal impairment

Renal impairment means that your kidneys are not functioning normally. One of the major complications that can follow a liver transplant is a sudden loss of kidney function. This is known as acute renal failure and affects as many as one in four people.

Renal impairment makes it much more difficult for doctors to manage your disease. It may be reversible if doctors can diagnose it early enough, so it is important that problems are identified quickly and properly treated.

What causes renal impairment?

The general effects of immunosuppression can weaken your kidneys. The use of cyclosporin and tacrolimus is known to affect

the kidneys by reducing blood flow and causing a type of fibrosis (scarring) to occur.

To treat this and stop kidney function getting worse, doctors will reduce the dosage of CNIs and prescribe other effective but less toxic drug combinations. Immunosuppressants such as sirolimus and mycophenolate work differently to CNIs and do not affect the kidneys to the same degree. Doctors may use these drugs instead of or in combination with a low dosage of CNIs.

While more research needs to be carried out, certain factors can help doctors to predict whether you are likely to progress to chronic kidney disease (CKD). The main 'predictors' are:

- having renal failure in the first three to twelve months following transplantation
- renal failure before your operation
- a history of cirrhosis and renal disease before your operation
- having taken cyclosporin or another CNI medicine and your body reacting to it
- having hepatitis C before transplantation
- having diabetes before transplantation
- high blood pressure (hypertension)
- your age and sex – CKD occurs more in older recipients and more commonly in women

Other known CKD factors are obesity and smoking

Where such risk factors are known, medical staff will work with you to reduce the chances of renal impairment or minimise the rate of development of chronic renal failure. Your kidney function is tested each time you visit your clinic. Close attention will be given to your glomerular filtration rate (GFR), levels of a protein called creatinine in your blood and evidence of proteinuria (an increase of protein in urine).

Malignancy

Immunosuppressant drugs reduce the body's ability to find and destroy abnormal cells that can lead to the development of malignancies, or cancers. With people now surviving much longer after transplantation and because the transplant population is getting older, malignancies are becoming an increasingly significant complication.

For this reason it is important that you take precautions to reduce the chances of developing cancers or to help early detection of malignant changes.

The most common malignancies are:

Lymphoproliferative disease

These are disorders such as such as lymphomas and leukaemia in which too many lymphocytes are produced or act abnormally. Lymphoproliferative disease is the most common malignancy arising from liver transplantation and may develop at any time.

Doctors will be on the lookout in all patients for signs of post-transplant lymphoproliferative disease (PTLD), such as swollen lymph glands and unexplained fevers.

Skin cancers

Exposure to the sun can damage your skin and increase the chances of developing skin cancer. This means avoiding the midday sun (10am to 3pm) when the ultraviolet rays are the strongest and applying a sunscreen lotion on uncovered skin (especially your face, neck and hands) when outdoors. Wear a hat, long sleeves and trousers if you are not using a sunscreen.

If you notice any changing spots, blemishes or moles on your skin, report this to medical staff immediately.

Cervical cancer

The detection and treatment of cervical abnormalities through screening programmes can prevent the development of cervical cancer. All women aged between 20 and 64 years should be offered a cervical smear test every 3 years at their GP clinic. Women on immunosuppressant drugs are advised to visit their GP or local clinic for a smear once a year.

Colorectal carcinoma

Ulcerative colitis is an inflammation of the colon that produces ulcers in its lining. If your liver disease is associated with this condition it is advisable that you are screened for colon cancer by colonoscopy examination every year. There are studies that suggest people who undergo transplantation for primary sclerosing cholangitis (PSC) should also be screened annually for this cancer.

Oropharyngeal carcinoma

Sometimes called throat cancer, this malignancy develops in the part of the throat just behind the mouth, called the oropharynx. Immunosuppression is considered to increase the risk of oropharyngeal carcinoma and is more commonly seen in people who have transplants for alcohol related reasons.

Hepatocellular carcinoma (HCC)

Hepatocellular carcinoma (HCC) is a primary liver cancer that is becoming more common in the UK due to increased incidence of chronic hepatitis C infection. People with a background of chronic hepatitis B, haemochromatosis, autoimmune liver disorders or alcoholic cirrhosis also have an increased risk of developing this malignancy.

As with many liver diseases HCC has the potential to return after treatment. However, liver transplantation is increasingly regarded as an effective treatment to stop tumours returning. This is provided that

tumours are small (no larger than 5cm in diameter) and you have no more than three (no larger than 3cm) before your transplant.

Cardiovascular risks

People who have had a liver transplant are more likely to be at risk of cardiovascular disease than the general population, and have a higher predicted risk of developing coronary heart disease (CHD).

Not only will doctors have to manage these risks but they – and you – must make sure that your cardiovascular health is as good as it possibly can be to help your body cope with the stress of immunosuppression.

The factors that doctors will consider are:

- your age, sex, height and weight
- whether you smoke
- hypertension
- having diabetes before your transplant
- a family history of cardiovascular disease
- any medication you may be taking

CNI and steroid-based immunosuppression regimens used after transplantation can cause an increase in fluid retention and increased appetite. For this reason they are linked with the development of hypertension and hyperlipidemia (excessive blood fats), weight gain and type 2 diabetes.

In the first months after your transplant you will be on a no-added salt diet to prevent or manage any hypertension. You will be screened yearly to make sure levels of fats known as lipids (cholesterol and triglycerides) in the blood are within the guidelines and target levels set for you.

To avoid putting on extra weight and to exercise weakened muscles following your transplant, you are encouraged to increase your activity level and do some gentle exercise, where this is possible.

Although there are no long-term dietary restrictions following liver transplant, simple rules apply: cut down on fatty foods, sugar and salt, and eat more fresh fruit and vegetables

Diabetes

Diabetes is a condition that occurs when your body cannot regulate the amount of glucose in your blood. Glucose is a sugar produced when you digest your food. It is also produced and stored by your liver.

Blood glucose levels are regulated by insulin, a hormone produced by your pancreas. Problems start when your body either does not produce enough insulin or if the muscle, liver and fat cells do not respond normally to insulin. This latter is known as insulin resistance and leads to a high level of glucose in the blood (hyperglycemia), which is harmful.

Diabetes that develops after transplantation will last for only a small percentage of people. Many people will have glucose intolerance that goes away after steroids are reduced and stopped. Weight loss, too, is very important and often improves glucose tolerance.

Treatment is along the lines of that for non-transplant people with diabetes. Insulin is often required at first, but following a reduction in immunosuppression and corticosteroids, people can usually be switched from intravenous to oral medication.

Viral hepatitis

People with hepatitis B and – far more commonly – hepatitis C make up a large number of transplant recipients. The results of liver transplantation for people with hepatitis B virus with acute or chronic liver failure and/or primary liver cancer have improved greatly, due to advances in antiviral drugs. Following transplantation for hepatitis B, people are routinely given hepatitis B immunoglobulin (HBIG) and lamivudine together with other medications, to prevent the virus from re-infecting the new liver.

Hepatitis C (HCV)

In hepatitis C the new liver is very likely to become re-infected following liver transplantation. Levels of the virus are at their lowest immediately after transplantation but are likely to reach pre-transplant levels (and can be up to twenty times higher) within a few days of the transplant. It is now known that this happens more quickly than in pre-transplant people. This is due to their weakened immune system caused by high doses of immunosuppressant drugs.

Treatment for recurring hepatitis C is still developing, and doctors have to take great care in prescribing both hepatitis C and immunosuppressive drugs. Using antiviral drugs following transplant is aimed at stopping rapid viral replication and to limit damage to the liver. This is usually most effective for mild recurrence of infection but the number of people who report side effects is still high. The best timing for giving antiviral medication after transplantation and the most suitable dosages are still being studied by medical scientists.

As with normal hepatitis C infection, post-transplant recovery differs between one person and the next. After a few years some people may have persistent viraemia (detectable virus in their blood) with no significant liver damage, while others may have gone on to develop severe fibrosis and cirrhosis.

No single risk factor can be relied on to predict who will go on to develop cirrhosis after transplantation but medical investigation has focused on the following:

- a high viral load at the time of transplantation
- infection with genotype 1 (especially 1b) or 4
- the time between removal of the donor organ and its implantation in the recipient, known as ischemic time
- the age and sex of the donor – studies suggest progression increases with age and is common in women.

Unfortunately one in five people develop cirrhosis within a year of transplant and a small proportion die of hepatitis C-related liver disease within five years. However, the overwhelming majority of people who survive the transplant will live without serious damage from hepatitis C virus infection for the first five years.

Lifestyle issues

Having a liver transplant is a major life event and research shows that such a substantial physical and emotional change can put you under considerable stress. It is therefore common to experience a whole range of emotions and some people will experience psychological problems following their transplant. This is particularly likely for people without good support from family and friends, those who have had problems like depression before transplant and those with substance use disorders.

However, there are studies that show that people who receive a liver transplant also receive psychological benefits and are often happier than people who have not received a transplant, whether they are ill with liver disease or healthy. Many people who have problems before transplant, including memory impairment, slow reactions, anxiety and depression that are common in end-stage liver disease, find that the transplant helps these considerably.

The following section has brief information to answer the questions people commonly ask to help them with life following liver transplantation.

Alcohol

One of the reasons you will have had a liver transplant is to improve your health and quality of life. However, because alcohol is very much part of our culture and way of life, you will need to make decisions about how you approach alcohol in the future.

Alcohol use was not the cause of my liver disease – can I still drink?

In general, drinking alcohol after transplant is not recommended, even for people who have not had alcohol-related liver disease. Alcohol is broken down by the liver and so drinking alcohol places the liver under extra strain. In the first few months of transplant, it is especially important to protect your liver from extra strain so that it can recover from the transplant and enable the body to heal and liver function to return to normal.

For people who have had their transplants as a result of diseases such as Wilson's Disease or alpha-1 antitrypsin deficiency, the liver transplant may offer a complete cure. If there are no problems with the medications you are taking, it may be possible to return safely to moderate alcohol consumption. It is best to seek advice from your transplant centre about if and when it is safe to start drinking alcohol.

For most people, however, the transplant will be a treatment rather than a cure for their liver condition. There is a risk that autoimmune conditions, hepatitis B and C, and NASH can recur in transplanted livers. Consuming alcohol places the liver under further strain and can accelerate the damage that is caused by these conditions. There is further advice in the section below about living without alcohol.

I have had alcohol related liver disease – can I still drink?

If you have had a liver transplant because of alcohol related liver disease you will have been asked to remain alcohol free for the rest of your life. There are several reasons for this.

- Your transplanted liver may not be able to break down alcohol as effectively as your own liver because of the immunosuppressant drugs you are taking. This could mean that relatively small amounts of alcohol could damage your transplanted liver in quite a short period of time.
- It is possible that if you started drinking alcohol again you might find it hard to stick to just one drink. When this happens a person can find that they start drinking much more than they intended and quickly go back to drinking at levels that caused their original liver disease.
- Some people may have undesirable consequences of starting to drink alcohol again. This might include such things as forgetting to take your medication, missing appointments or effects on other aspects of your care. This could affect your transplanted liver and in some cases lead to rejection.

When you were being considered for a liver transplant it is likely that you have signed an agreement to remain alcohol free after your transplant. This is done to help remind you about the importance of not drinking and the reasons why you agreed to be abstinent. It is also part of your acceptance of all the treatment and care offered to you and a demonstration of your commitment to the transplant programme. The agreement is also likely to highlight the need to maintain contact with the alcohol liaison specialist within the transplant team as well as having routine blood tests to check for alcohol. It is worth remembering that this contact enables the transplant team to spot any potential problems earlier and so offer support and treatment sooner, reducing the likelihood of harm to the new liver.

The most important thing is that you understand the cause of your liver disease and take a decision not to drink alcohol again.

What about shandy or alcohol free drinks – surely they can't hurt?

People who have had a history of alcohol related liver disease should not drink low alcohol or alcohol free drinks. You might think this seems a bit harsh but,

- Sometimes drinking alcohol free drinks such as Kaliber or Becks LA can trick your brain into thinking that you are really drinking alcohol. When this happens it can cause a desire or craving to drink alcohol again.
- When you are in a social situation or at the pub it is possible to get drinks mixed up and find you have mistakenly drunk some alcohol without meaning to. This risk is reduced if you stick to soft drinks.
- Shandy does contain alcohol. Some people have found that they started drinking a shandy that was mostly lemonade and a tiny bit of lager. Over the course of time the lager can become the bigger part of the drink and you can end up drinking far more than you originally intended. This may cause a return to your original liver disease.
- There are many more types of soft drinks available than in the past. Take your time to experiment with these to find one that you enjoy and feel comfortable with.
- If this is bothering you or you have further questions, talk to the substance misuse nurse at your transplant centre or your liver transplant coordinators.

How can I manage without drinking alcohol?

Before you had your transplant it may have been relatively easy not to drink alcohol. You were probably feeling unwell, had less of a social life and were very aware of the need for abstinence as part of being on the liver transplant waiting list. As you return to a more normal life you may find it harder than you expected not to drink. Below are a few ideas that you might find helpful.

- Reduce the temptation to drink. Don't keep any alcohol at home, particularly in the fridge.
- Identify your triggers. These can be certain people or places. Often triggers can be the way we feel, such as when we are stressed, angry, anxious or down. Try to avoid your triggers if you can, or develop a plan so that you are prepared and able to deal with a situation without alcohol.
- If your triggers for drinking are difficult feelings such as anger, anxiety or depression, it may help to talk to someone about managing these without drinking. Most of the organisations that work with people to stop them drinking have skills and practical advice to help you with this.
- Look back at your list of reasons for stopping drinking and remind yourself regularly about why you are giving up alcohol. Remember it is not just about the transplant – you may have noticed other unexpected benefits such as having more money, developing new interests and having better relationships with those you love for example.
- Keep busy! Boredom is often a reason for drinking or returning to drinking. Think about hobbies you have neglected or you want to take up.
- Change your habits. If having a drink straight after work was something you always did, you will need to alter your routine. Do something else or find another way to relax.
- Take it one day at a time. It can be very daunting to think about not drinking forever. When it gets difficult try saying to yourself, 'I'll just not drink for today.' If that feels too much, break it down to 'Just for this morning' or 'Just for the next couple of hours'.

- Cravings or urges to drink will pass. You might find it helpful to remember the ‘four Ds’:
 1. Delay for at least five minutes so that the urge to drink will pass
 2. Drink some water or soft drink you like, and sip it slowly
 3. Deep breathe – slow, full deep breaths will control your nerves
 4. Distract yourself, do something else to keep your hands and mind busy.

Do also talk to friends, family or alcohol support such as alcohol counsellors, alcoholics anonymous or contact telephone helplines such as Drinkline.

- Don't try to test yourself. It might seem a useful challenge to deliberately go somewhere you know you might be tempted to drink to see if you can manage to stay off it, but this can be quite dangerous and can lead to a slip back into old drinking habits.
- Tell close friends and people who you see often about not drinking alcohol and why this is important to protect your health. If you do this, they are likely to be more understanding, put less pressure on you and will make sure that they have a suitable soft drink available for you when you see them.
- Be convincing! When you are in a social situation be clear about which soft drink you are having, ask confidently and don't hesitate. If you seem unsure people are more likely to try and persuade you to drink alcohol instead. It is worth preparing ahead and thinking through scenarios and how you will respond.

Being alcohol free is part of a whole range of things that you need to do in order to keep yourself healthy after your transplant. It is important to take regular exercise and eat a balanced diet especially as some of the side effects of the immunosuppressants make weight gain easier. Remember alcohol contains lots of calories – even a pint of very weak beer (3.5% abv) can contain up to 180 calories. Exercise is also a useful way of managing stress as well as controlling your weight.

Can I use illicit drugs after transplant?

Many of the reasons for not using recreational drugs are similar to the reasons for not using alcohol post transplant. There may be a tendency to use more of a substance than intended, and under the effects of the drug you might forget to take your immunosuppression medication or keep your hospital appointments (or perhaps simply misjudge them as not very important).

All drugs have an effect on the liver, but in particular, street drugs are notoriously impure, often of unknown strength and frequently containing one or more other drugs as well as contaminants. Whatever the route of administration, these drugs will impact on your judgement, behaviour and the liver.

Surely cannabis is OK?

Cannabis is a psychoactive drug. It can aid relaxation (though may also induce anxiety and paranoia). It is linked to untoward effects on motivation and judgement. It is also linked to the "gateway theory", where people who start using this drug may move onto other harmful drugs. There are some clinical reports of direct effects on the liver. As such, the use of cannabis is actively discouraged.

I am on a methadone programme. Should I stop it?

Some patients who have used opiates in the past (such as heroin) are treated with a substitute medication such as methadone or buprenorphine (Subutex).

Substitute medication is aimed at helping a person to manage cravings for opiates and provide a safer alternative to illicit or unmanaged use. If you are on a methadone or Subutex programme it is likely that you will be under a treatment team for this, either within a drugs clinic or your own GP surgery. It is very important that you do not stop your medication unless you do so as part of a planned

detoxification with your drug treatment team, or because your medical team need to stop it for medical reasons. In the case of the latter, your medical team should discuss this with you and your drug treatment team and be aware of the possible complications of this, which could include opiate withdrawal symptoms, reduced tolerance to opiates and craving to use drugs again.

There is also good evidence that people who stop using opiate drugs such as heroin and methadone may sometimes substitute for this by increasing their alcohol use, and so you, your family and your treatment team should be mindful of this.

Alcohol and drug misuse

There are about 500 local advice and counselling centres in the UK. Most of these are funded by the NHS and are free to access. You can look them up in the telephone book or use the directory on the Alcohol Concern website (details below). Alternatively your GP or practice nurse should be able to provide you with details of your local service and arrange to refer you, though in the majority of instances self referral is preferred and more straightforward.

Alcohol Concern

64 Leman St

London E1 8EU

Tel: 020 7264 0510

E-mail: contact@alcoholconcern.org.uk

www.alcoholconcern.org.uk

A national agency on alcohol misuse, Alcohol Concern provides information on issues affected by alcohol.

www.downyourdrink.com

A website designed to help you work out whether you're drinking too much, and if so, what you can do about it.

www.drinkaware.co.uk

A range of information and useful resources for sensible drinking and advice about alcohol.

Drinkline (The National Alcohol Helpline)

Tel: 0800 917 8282 (open 9.00am to 11.00pm Monday to Friday)

A free telephone helpline service offering information and self-help materials to callers worried about their own drinking, support for family and friends of heavy drinkers and advice on where to go for help.

Frank (formerly the National Drugs Helpline)

Tel: 0800 77 66 00

www.talktofrank.com

A 24 hour free telephone service and website offering information and advice on drugs and drug misuse. A literature and referral service is also available to helpline callers.

Narcotics Anonymous (NA)

0800 373 3366

<http://www.ukna.org/info/contacts.htm>

Alcoholics Anonymous (AA)

0845 769 7555

<http://www.alcoholics-anonymous.org.uk>

Living everyday life

Diet after liver transplant

You will probably find that you have a better appetite after transplantation than you did before the surgery. Some of the weight gain is also due to the immunosuppressive medications – particularly prednisone. However, for around a third of people after transplant, this is significant (over 10kg or 1.5 stone).

To stay at a healthy weight, it is sensible to reduce your consumption of simple carbohydrates such as food and drink high in sugar. Eating complex carbohydrates such as cereals, vegetables, whole grain pasta, bread, rice and potatoes is a healthier choice. It is also helpful to restrict how much fat you eat, not just to limit weight gain but also to help control your cholesterol which can be a particular challenge when taking some anti-rejection medications.

It is also important to eat sufficient protein to enable your wounds to heal and to build muscle. You may be advised to eat roughly 80g a day of protein, spread over several meals if possible. Protein is found in meat, poultry, fish, eggs, nuts and beans.

Your transplant centre can give you specific dietary advice and refer you to a dietician for any specific problems you have.

When can I go back to my usual routine?

Having a liver transplant is a major operation and people need time to recover. How much time depends on the individual and it can vary from six weeks to six months before people are ready to take up normal activities again. It is a good idea to reduce the length of time you do various activities, such as work, school or exercise, so you can build up your strength. You will probably find that you get tired more easily and it is important to be able to rest whenever you need to.

When can I take up exercise?

Taking up a healthy lifestyle with exercise built-in is an important part of your recovery from a transplant. However, it is important to build

up your levels of activity gradually and it will take time to build your strength and endurance. You should avoid strenuous exercise for the first couple of months and check with the transplant centre that this will not cause problems. It is important not to lift heavy items until your wound has healed and for at least the first two months after transplant. Contact sports, such as boxing, should generally be avoided.

What about travel?

You will be advised not to travel long distances away from your transplant centre in the early weeks. After this, it depends on your health and where you are travelling to. Some destinations may put you at increased risk of infection, from anything such as food poisoning bacteria to malaria and you may not be able to receive some of the necessary prevention mechanisms such as live vaccines. It is best to seek medical advice about whether travel to these destinations is advisable at all.

When you travel, always take contact details for your transplant centre with you so you can contact them for advice when you are away. Sensible precautions such as not travelling if you feel ill, seeking prompt medical advice if you are unwell when away (and telling them you have had a liver transplant), and taking a written list of all your medications and doses are very important.

It is important to remember that your travel insurance will not cover you (or anyone travelling in your party) for health problems that arise, cancellation, or the need to return home early, unless you have specifically briefed them about your medical history and they have agreed to cover. If you do not have health insurance, it is a good idea to check the cover that might be provided to you in an emergency and whether they have any reciprocal agreements for healthcare, such as participation in the European Health Insurance Card scheme.

Will I be able to have a normal sex life after liver transplantation?

As soon as you feel ready! Transplantation can affect sexual function – men can find that it can take a couple of months for everything to work normally again. Certain medications, too, can have an effect. If you have any problems or concerns you should talk about these with your transplant team when you come to clinic.

Women are not recommended to use oral birth control pills immediately after transplant, and for both men and women, it is important to use contraception because conceptions must be carefully planned if you have had a transplant (see below).

Both women and men have a higher risk of contracting sexually transmitted diseases (STDs) if on immunosuppressants, so take extra care and practice safe sex.

Can I have a baby following liver transplantation?

If you are considering trying for a baby, speak to your transplant team for advice. Some medications (particularly mycophenolate mofetil (CellCept)) can harm the unborn child, so it is important that they review and possibly adjust your medication regime before you get pregnant. It is vital that you do not stop taking your immunosuppressants when you become pregnant without speaking to your transplant team. In general it is thought that you should wait at least 12 months following your transplant before attempting to conceive.

The good news is that many women have become pregnant and have had healthy children after transplant. Perhaps unsurprisingly, complications are more common in liver transplant recipients than in the general population. As a result, such pregnancies should be followed by a multidisciplinary team involving both obstetric and transplant specialists.

Planning ahead

This publication has been designed to help you live life after a liver transplant, manage the risks of complications and live a healthy lifestyle. It is important to be realistic about life with your new liver and be patient with yourself. Years of living with a serious liver problem, the uncertainty about receiving a transplant and the major physical and emotional toll of the operation itself can take a toll on liver patients and their families. The transplant will not be able to address all these problems and we recommend setting achievable goals and having reasonable expectations of how the transplant can help you live life to the full.

There are many factors you can manage with the support of your family and transplant team. Staying healthy, eating well, attending clinic, taking exercise, getting enough sleep, taking your medicines and raising concerns promptly with the medical team are all important. Managing your stress levels and keeping a positive attitude are key to maintaining your emotional as well as physical health.

Complementary and alternative medicines

Many complementary and alternative medicines are available that may ease the symptoms of liver disease. But certain medications used in non-liver related disease can damage the liver. At present, healthcare professionals are not clear on the role and place of some therapies in managing liver disease. More research needs to be done on the use of these therapies. You may wish to discuss the use of these therapies with your doctor.

Useful words

Acute – a short sharp illness that may be severe but from which most people will recover in a few weeks without lasting effects.

Anaemia – a condition where there are not enough red blood cells taking oxygen around the body, causing symptoms like fatigue and shortness of breath.

Autoimmune disease – a type of disease where the body's defences attack another part of the body.

Bile – a yellow-green fluid produced by your liver to aid digestion. It contains chemicals as well as waste products and plays a central role in helping the body digest fat.

Chronic – an illness that lasts a long time (more than six months), possibly for the rest of a person's life.

Cirrhosis – where inflammation and fibrosis have spread to disrupt the shape and function of the liver. Even with no signs or symptoms of liver disease, the working capacity of liver cells has been badly impaired and they are unable to repair the liver. This is permanent cell damage and can lead to liver failure or liver cancer.

Creatinine – a waste product from protein in the diet and from the muscles of the body. Creatinine is removed from the body by the kidneys. Measuring the creatinine level in the blood gives an indication of how well, or poorly, the kidneys are working.

DNA – deoxyribonucleic acid, the chemical compound of which chromosomes are made and which contains the genetic instructions for the making of proteins in your body.

Fibrosis – where scar tissue is formed in an inflamed liver. Fibrosis can take a variable time to develop and, even with scar tissue present, the liver keeps on functioning quite well. However, continued building up of scar tissue may lead to cirrhosis.

Glomerular filtration rate (GFR) – a test of kidney function that measures the effectiveness of the glomerulus, a small, entwined group of tiny blood vessels (capillaries) in the kidneys, to filter urine from your blood. A reduction in the GFR increases the risk of renal failure.

HBIG – hepatitis B immunoglobulin, a product made from plasma which contains antibodies to hepatitis B virus. HBIG offers rapid but temporary protection against infection.

Hyperlipidemia – having excessively high levels of fats (triglyceride and cholesterol) in the bloodstream.

Inflammation – the body's protective reaction to injury, involving swelling, pain, redness and heat.

Intravenous – injection of a fluid into a vein via syringe or catheter (a long narrow tube inserted into a vein to allow intravenous injection).

Liver function tests (LFTs) – a panel of tests used to indicate whether your liver is inflamed (hepatitis), damaged or not working properly. They measure levels of certain enzyme and protein substances in your blood that may alter when liver damage is present.

Lymphocyte – a small white blood cell (leukocyte) that plays a large role in defending the body against disease.

Lymphoproliferative – refers to disorders in which lymphocytes are over-produced or act abnormally.

Malignant – a tendency to become progressively worse. In tumours, this describes a disease that will spread and destroy healthy tissue.

NASH – non-alcoholic steatohepatitis is a form of non-alcoholic fatty liver disease where an inflammatory response accompanies the fat. This may cause scarring to the liver and can progress to cirrhosis

Portal hypertension – increased blood pressure in the portal vein, which carries blood from the bowel and the spleen to the liver. Portal hypertension is characterised by impaired or reversed blood flow, an enlarged spleen, and protruding (dilated) veins in the oesophagus and stomach.

Prophylaxis – treatment to prevent the onset of a particular disease or the recurrence of symptoms in an existing infection.

Who else can help?

Support groups

There are numerous support groups around the UK. Support groups can offer support, counselling and an opportunity for you to share your experience with others. You will also meet and talk to plenty of people who have lived many years with their transplant. This can help if you are finding the whole transplant process quite daunting. If your local transplant unit does not have a link to a local support group, contact the British Liver Trust for details of your nearest organisation.

Liver Transplant Support

Westlake Farm

Monkokehampton

Winkleigh

Devon EX19 8AX

Tel: 0845 270 7760 (please email in the first instance)

Email: info@livertransplantsupport.org

www.livertransplantsupport.co.uk

On-line advice and information for potential liver recipients from people who have first hand experience of transplantation – ‘help by those who have been there’.

UK Transplant

Tel: 0117 975 7575

Email: enquiries@uktransplant.nhs.uk

www.uktransplant.org.uk

Part of NHS Blood and Transplant and the official NHS transplant site. It provides news, information and resources about organ transplantation, real life stories from those who have benefited from transplants and a facility for potential donors to sign on to the organ donor register.

Transplant Support Network (TSN)

6 Kings Meadow Drive

Wetherby

West Yorkshire LS22 7FS

Telephone support line: 0800 027 4490/4491

Email: tsnetwork@tiscali.co.uk

www.transplantsupportnetwork.org.uk

Nationwide network and registered charity supporting patients, family and carers of all solid organ transplants and mechanical implants.

Live Life Then Give Life

www.livelifethengivelife.co.uk

A charity that raises public awareness of organ donation and the chronic lack of organ donors in the UK.

The Transplant Trust

www.thetxspace.com

A national charity that raises awareness of organ and tissue donation by encouraging people to talk about, and register, their willingness to donate.

Further information

The British Liver Trust publishes a large range of leaflets about the liver and liver problems written for the general public. Leaflets that you may find particularly helpful include:

- *Alcohol and liver disease*
- *Autoimmune hepatitis*
- *Cirrhosis and liver disease*
- *Diet and liver disease*
- *Hepatitis B*
- *Hepatitis C*
- *Liver cancer*
- *Liver disease tests explained*
- *Primary biliary cirrhosis*
- *Primary sclerosing cholangitis.*

Contact us for more information:

Tel: 0800 652 7330

Email: info@britishlivertrust.org.uk

Web: www.britishlivertrust.org.uk

Special thanks

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Can you make a difference?

Liver disease is increasing alarmingly and the need to do more is greater than ever before.

For the British Liver Trust to continue its support, information and research programme, we need your help. We raise funds from many sources and a large proportion is donated by voluntary contributions. If you would like to send a donation it will enable us to continue providing the services that people need.

If you can help, please fill in the form on the page opposite.

If you wish to help us further with our work by organising or participating in a fundraising event or becoming a **“Friend of the British Liver Trust”** please:

**Call us on
0800 652 7330**

**Email us at
info@britishlivertrust.org.uk**

**Make a donation via our website at
www.britishlivertrust.org.uk**

**or write to
British Liver Trust
2 Southampton Road, Ringwood, BH24 1HY**



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Please send me more information

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