Liver Transplantation Book 2
Information for patients
This booklet gives you advice on living with your transplant, how to avoid problems and how to make the most of your new lease of life.

We are delighted that you have received a transplant and are now able to recover. We have tried to answer many of the common questions which patients ask. However, if you have any other questions, no matter how silly they may seem, do ask us and we will try to help. In this book we have included information about the medicines you will need to take, followed by advice about your diet, general health and daily living.

We have also included a section which gives details of the information available through the social services department. We hope you find this booklet informative. If you feel there is anything further we could include please let us know.
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Section 1 - Introduction

Your liver is the largest organ in your body. It is found on the right hand side just behind the lower ribs.

It performs many essential functions to keep the rest of the body working correctly:

- It produces bile and delivers this via fine tubes called bile ducts, into the bowel to help digestion and absorption of vitamins and fats.
- It controls the amount and type of food circulating in your bloodstream.
- It converts damaging substances you eat or which your body makes, into harmless products, which can easily be removed from your body.
- It makes clotting factors to stop you bleeding and various other proteins, some of which help fight infections.
- It controls levels of hormones in your blood.
- It metabolises (processes) many drugs.
- It makes most of the proteins your body needs.
- It stores many important vitamins.
- It is the powerhouse or engine for the body.
- It is the first line of defence for infections coming from the gut.

The liver can be affected by many different diseases, which can be chronic or acute disorders.
Chronic Liver Failure
This deterioration is gradual and takes many years before the liver is damaged severely enough so that the liver transplant needs to be considered.

As the disease has been worsening over time, it is hoped that you and your family have had more time to prepare for and accept the need for a liver transplant.

For instance you may have spent time in hospital and undergone a series of tests, met other patients who have already had a liver transplant, and also been introduced to members of staff on the liver unit.

Acute Liver Failure
This process involves the rapid onset of symptoms and destroys the liver in a short period of time.

If you have acute liver disease the decision to have a liver transplant will come as a shock to both you and your family.

In some cases it can be that the patient is so severely ill that they are oblivious to what is actually happening and the family are the ones who feel the impact of the situation.
Section 2 - General Information & Contacts

Transfer to the liver unit

- The number of drips and machines will gradually be removed when they are no longer required - allowing you to be more independent.

- As part of your rehabilitation you will be getting out of bed within a few days. Although this may seem harsh it is important to prevent chest and mobility problems. After all you are now on the road to recovery.

Pain

This may be a concern to patients undergoing transplantation. A feeling of a ‘stinging’ or ‘pulling’ can be felt at times, but it is nothing to worry about and can be controlled with painkillers. You will be given a drip with a button to press in order for you to control the amount of painkiller you receive. It is normal to feel discomfort rather than pain around the wound and drains.

Once the intravenous pain killer is discontinued you will be given pain relief by mouth.

Constipation

This can be a problem, but eating a high fibre diet can reduce this. There will also be discomfort around the abdominal area. Wind and abdominal distension from the surgery is common but it does lessen as time passes.

Getting out of bed and walking will aid the return of normal bowel function.
Recovering from the operation

It’s important to remember recovery is different for each patient.

Some patients experience confusion in the immediate post-operative phase. This is not uncommon, particularly for patients who have suffered confusion before transplant. This tends not to last more than a few days.

Fluid retention to varying degrees can be experienced after your transplant. You may notice swelling of your legs and abdomen. This does resolve, but can take time. It’s important you walk short distances regularly and put your feet up when resting.

Slowly you will begin to feel better, but may tire quickly. Relax and put your feet up each day. Don’t compare yourself to other patients, everyone recovers differently. Concentrate upon the positive aspects - you are on the road to recovery. The most important thing is to take each day as it comes and listen to advice given by the doctors and nurses caring for you.
Medication

You will be on a variety of medications initially, ranging from anti-rejection medication to antibiotics and painkillers. These are a vital part of the transplant process. It may be difficult to get used to the names and functions of the medications, but the self-medication scheme on the ward is helpful.

Take your time and seek assistance from the nursing and pharmacy staff. Eventually you will find taking the medication to be an automatic and natural part of your daily routine.

Going home

Going home following your transplant can be an overwhelming experience.

Patients sometimes describe feelings of anxiety at having left the safety of the hospital, where there is always a member of staff available to allay any fears.

It is important to remember you would not be discharged until the transplant team felt it was safe for you to go home.
Out-patients Clinic

On your discharge home from hospital your GP will be sent a letter about your transplant and treatment.

The clinic is held every Tuesday morning in the Surgical Outpatients Suite on the ground floor of Bexley wing, run by the transplant team.

Initially you will be asked to come weekly then the visits will become less frequent.

When you come to clinic, please do not take your ciclosporin or tacrolimus that morning, but bring it with you so that you can take it as soon as your blood has been taken. This is because we monitor your blood levels to ensure you are getting the right amount of anti-rejection medication and may need to adjust your dose.

Occasionally it is necessary for you to be admitted to hospital for a review of your blood results or a change of medication. Although this may be disappointing to you, as you may have thought everything was going well and you feel healthy, it is important to realise that it is only a minor setback and early treatment is vital.
Rejection

Although one in three people will have an episode of acute rejection after their operation, this is usually treatable without any long term consequences. These episodes are more common in the first year following transplant. Most patients will not have any symptoms of rejection, which is why it is important you attend regularly for blood tests. An abnormality in your liver tests may be the only indication of rejection. If this is suspected it may be necessary for you to be admitted to hospital for a liver biopsy and further treatment.

If you do not have blood monitoring you may have undiagnosed rejection which may lead to chronic rejection. Even with regular monitoring a small minority of patients may develop chronic rejection.
Section 3 - Information about your medicines

Introduction
Medicines are an essential part of your treatment after your liver transplant. Whilst you may need to take some medicines every day for the rest of your life, such as anti-rejection medication, others started post-transplant will only need to be taken for a limited time after your transplant.

If you are admitted to hospital (either St. James’s or a local hospital) always take your current medicines with you.

The main types of medicines are:

- Anti-rejection medicines (immunosuppressants)
- Anti-ulcer medicines
- Medicines to prevent infections (antibiotics)
- Pain killers
- Aspirin to prevent blood clots
- Calcium and Vitamin D supplements
- Sometimes, blood pressure tablets
- Sometimes, blood sugar medicines

Anti-Rejection Medicines/ Immunosuppressants

Your body’s normal response to anything that it sees as a foreign object is to attack it. This helps us stay healthy and fight infection. After a transplant, your new liver will be seen by your body as foreign and your immune system will automatically attack it. This is called rejection. To prevent this happening you will need to take anti-rejection medicines (also called immunosuppressants).
You will need to take at least one immunosuppressant for the rest of your life. If you stop taking these very important drugs, it is very likely that you could develop rejection and lose your transplanted liver.

Because immunosuppressants affect your immune system, they reduce your body’s ability to fight infection. You should try to avoid being in contact with people with coughs and colds and other types of infections.

Taking immunosuppressants also increases your chances of developing certain types of cancer, including skin cancer. You need to follow safety advice on protecting yourself from the sun and examining your body regularly.

Despite the disadvantage of immunosuppressants, the benefits of a transplant outweigh the long term problems.

You will usually be on two or three of the following:

- Tacrolimus (e.g Adoport® or Advagraf®) OR Ciclosporin (Neoral®) - never both together
- Mycophenolate Mofetil OR Azathioprine - never both together
- Prednisolone
- Sirolimus (not usually given immediately post-transplant)

The amount or dose of anti-rejection medication that you take is very important. If you take too little there is a risk of rejection, if you take too much you may get more side-effects. Always take the dose you have been prescribed by the doctor.
The different types of immunosuppressants will be discussed in turn. You should read the patient information leaflet enclosed in the packets of medicines. For further information or ask to speak to a pharmacist.

**Tacrolimus**

- You will usually be started on tacrolimus. This is the strongest type of immunosuppressant and the one you will probably take for the rest of your life. Tacrolimus works by blocking the production of cells that attack the new liver.

- **There are different brands of tacrolimus and it is very important that you remain on the same brand of tacrolimus that your hospital specialist starts you on. You must not switch between different brands unless your hospital specialist tells you to do so.**

- There are two different types of preparation for tacrolimus, immediate release (which you take twice a day) and prolonged release (which you take once a day). Again it is very important that you know which preparation you are on and that you do not inadvertently switch between the two.
1) Immediate-release Tacrolimus (e.g Adoport®/ Prograf®)
This preparation is taken twice a day, about twelve hours apart. Choose times suitable to you e.g. 8am and 8 pm or 10am and 10pm. Swallow the capsules whole with a glass of water, if possible an hour before or two hours after food. Some patients find it easier to take with food. If you do this, it is important to take at the same time in relation to food each day.

2) Prolonged-released Tacrolimus (e.g Advagraf®)
This preparation is taken once a day, in the morning. It is not usually started immediately post-transplant. Swallow the capsules whole with a glass of water, if possible an hour before or two hours after food. Some patients find it easier to take their tacrolimus with food. If you do this, it is important to take it at the same time in relation to food each day. The dose will be altered according to how much of the drug is in your blood, this is checked by a blood test just before you take your dose. As time goes by, if your new liver is working well, we can reduce the dose.

• During your hospital stay and when you visit the outpatient clinic we will take blood samples to measure how much tacrolimus is in your blood.

• On clinic days, do not take your tacrolimus before you come to clinic. Bring your capsules with you to hospital and take them after you have had your blood tests.

• If your blood tests show that you need to have your dose changed (up or down), you will be contacted following your clinic visit.

• All types of tacrolimus preparation come in capsule form and are available as different strengths.
Immediate release tacrolimus comes in 0.5mg, 1mg and 5mg. Prolonged release tacrolimus comes in 0.5mg, 1mg, 3mg and 5mg.

Make sure you are taking the correct brand of tacrolimus as they are different and are not interchangeable.

Side-effects of tacrolimus
Tacrolimus has several side-effects but not everyone will experience them. Some of the side-effects disappear as the dose of tacrolimus is reduced over time.

Listed below are the most common side-effects:
- Tremor (shaking) of the hands
- Headache
- Vivid dreams
- Upset stomach
- Hair loss on head
- Numb, hot or tingly hands, feet or mouth
- Diabetes
- High blood pressure
- Reduced kidney function

You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution. Your blood pressure and kidney function will be checked in clinic so changes can be made if needed.
Your blood sugars will be checked while you are in hospital to see if you have developed diabetes. You must tell the doctor in clinic if you are feeling unusually thirsty or passing increasing amounts of urine, because this may be a sign of diabetes.

**Taking other medicines with tacrolimus**

Some medicines can increase or decrease your tacrolimus level in the blood. This may either increase your chance of side-effects or rejection.

Always check with your doctor or pharmacist if you are prescribed or you buy any new medicines over the counter, including herbal medicines.

There are various medicines that you should **NOT** take whilst on tacrolimus, some examples include;

- Antibiotics called erythromycin and clarithromycin
- Non-steroidal anti-inflammatory drugs such as ibuprofen or diclofenac (can affect your kidneys).
- Some antifungals

Always check with a doctor or pharmacist that any new medicine is safe for you to take. If you are in doubt, contact one of the hospital pharmacists.

You should avoid eating grapefruit or drinking grapefruit juice whilst you are taking tacrolimus because it contains a chemical that affects the level of tacrolimus in your blood.

Other citrus fruits are safe to eat or drink.
What to do if you forget to take a dose of Tacrolimus

A missed dose of tacrolimus should be taken at least six hours before the next dose is due. If there is less than six hours before your next dose, then do not take that missed dose and carry on with the next dose at the normal time. **Never take a double dose to make up for missed doses.**

Mycophenolate

Mycophenolate reduces the number of white cells in the blood which play an important role in rejection. You will only ever take azathioprine OR mycophenolate, never both together. You may need to take mycophenolate for the rest of your life. There are two different preparations of Mycophenolate, one is called mycophenolate mofetil and the other is mycophenolate sodium which is enteric coated:

- Mycophenolate Mofetil is available as 250mg capsules and 500mg tablets and a liquid, 1gram/ 5ml. It is available in different brands and it is alright to switch between any brand.
- Mycophenolate Mofetil should be taken twice a day, every morning and evening, 12 hours apart. Swallow the tablets/capsules whole (without chewing) with a glass of water.
- Mycophenolate sodium (Myfortic®, Ceptava®) is available as a 180mg tablet and a 360 mg tablet.

Initially after transplant you will be started on Mycophenolate Mofetil.
**Side-effects of mycophenolate mofetil**

The most common side-effects are:

- Stomach upset (diarrhoea and vomiting) Taking the medicine with or just after food can help.
- Reduced white cell count (increasing risk of infection).
- Unexplained bruising.

*It is important to inform your doctor if you develop signs of infection whilst taking mycophenolate.*

**Taking other medicines with mycophenolate**

Some other medicines can reduce the amount of mycophenolate that is absorbed into the body. We recommend not taking iron supplements or antacids containing magnesium or calcium (e.g. Maalox®, Gaviscon®) within 2 hours of taking mycophenolate.

Colestyramine, a medicine used to reduce cholesterol or bile acid can also affect mycophenolate absorption.

Always check with a doctor or pharmacist that any new medicine is safe for you to take.

**What to do if you forget to take a dose of Mycophenolate**

A missed dose of mycophenolate should be taken at least six hours before the next dose is due. If there is less than six hours before your next dose, then do not take that missed dose and carry on with the next dose at the normal time. **Never take a double dose to make up for missed doses.**

*The use of mycophenolate is not recommended in pregnancy.*
• Female patients are advised to use 2 forms of effective contraception whilst taking mycophenolate and for 6 months after stopping treatment.

• For male patients (including those who have had a vasectomy) the use of contraception by either partner should continue during treatment and for 3 months after stopping treatment.

Azathioprine
Another type of immunosuppressant you may take after a liver transplant is Azathiporine. It acts to reduce the number of white cells in the blood which play an important role in rejection. Mycophenolate mofetil is a similar drug but you will only ever take azathioprine OR mycophenolate mofetil, never both together. You may need to take azathioprine or mycophenolate mofetil for the rest of your life.

Specific information about azathioprine
• The usual dose of azathioprine is between 50mg to 150mg once a day. It is usually better to take it after a meal.

• Azathioprine comes in tablets of 25mg and 50mg strength. Do not cut the 50mg tablets in half to get a dose of 25mg, always use a 25mg strength.

Side effects of azathioprine
Azathioprine has some side effects but not everyone will experience them.

• Stomach upset (take after food to reduce this)
• Reduced white cell count (increase chance of getting infections)
• Unexplained bruising
• Rash
• Hair loss

It is important to inform your doctor if you develop signs of infection whilst taking azathioprine.

Taking other medicines with azathioprine
Allopurinol should not normally be taken with azathioprine. Please tell the doctor if you are taking allopurinol as you will need a much lower dose of azathioprine.

Always check with a doctor or pharmacist that any new medicine is safe for you to take.

What to do if you forget to take a dose Azathioprine
A missed dose of Azathioprine should be taken at least twelve hours before the next dose is due.

If there is less than twelve hours before your next dose then, do not take that missed dose and carry on with the next dose at the normal time. Never take a double dose to make up for missed doses

Prednisolone
Prednisolone is an immunosuppressant and also a steroid. It is a corticosteroid which is not the same as an anabolic steroid, misused by some body builders. Corticosteroids are produced normally by your body. Prednisolone suppresses the immune system and inflammation and is used to treat many common diseases such as asthma attacks.
Prednisolone is usually only taken for the initial few months after a liver transplant. It is gradually reduced over a period of weeks and usually stopped completely unless you are already on it for a pre-existing condition before your liver transplant.

After taking prednisolone for more than a few weeks, your body will reduce the amount of steroid it produces. It is important that you reduce the dose slowly, as advised by your doctor. This will allow your body to start making its own corticosteroid.

You will be given a blue steroid card to carry around with you at all times. If you are having any surgical procedures, including dental treatment, inform your doctor or dentist beforehand.

Prednisolone should be taken once a day in the morning. Taking it with food may reduce the chance of indigestion.

**Side effects of prednisolone**

Prednisolone has a number of possible side effects. Most of the side effects happen slowly over a period of time. The doctors will reduce your dose to the smallest amount to prevent rejection. Most people will not take prednisolone after the first three months of their transplant.

- Stomach upset and indigestion (take with/after food to reduce this)
- Swollen ankles
- Weight gain due to increased appetite
- Rounded face
- Diabetes (increased sugar in blood)
• Thinning of bones (osteoporosis). You are likely to be started on calcium and vitamin D tablets to reduce this effect, if you are not already taking them.

• You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution.

**What to do if you forget to take a dose of Prednisolone**

If you forget to take your prednisolone but remember before 8pm, take it and then take your next dose at the normal time the following morning. **If you remember after 8pm, do not take your missed dose and take your normal dose in the morning.**

**Other types of medicines needed after a liver transplant**

**Anti-ulcer medicines**

To reduce the chance of you developing a stomach ulcer you will be started on an anti-ulcer medicine which works by reducing the amount of acid produced by the stomach.

If you have not had an ulcer in the past you will usually only take the anti-ulcer medicine for the period of time whilst you are taking prednisolone.

**Medicines to prevent infections (antibiotics)**

Anti-rejection medicines/Immunosuppressants can increase your risk of infection. To reduce this risk you will be given medicines for the first few months, when the doses of anti-rejection medicines are highest.

• Fluconazole capsules are taken to prevent fungal infections. You may take them for about a week after the transplant and they are usually stopped before you are discharged from the hospital.
• Co-trimoxazole (Septrin) tablets contain two antibacterial drugs called trimethoprim and sulfamethoxazole. They are given to prevent a particular type of bacterial pneumonia that people with reduced immune systems are susceptible to. The dose is one 480mg tablet daily for 3 months.

• Valganciclovir tablets are given to some patients to prevent a viral infection known as cytomegalovirus (CMV). The dose depends on your kidney function but is usually two 450mg tablets once a day. Take at tea time after food with a glass of water. Absorption of valganciclovir is increased with fat so this is usually taken with your fattiest meal of the day. While you are in hospital you will be supplied with the full quantity of tablets to complete the course at home.

**Pain killers**

You can reduce the pain killers when you are ready. It is usually wise to reduce any other analgesia first before starting to reduce the paracetamol.

> It is important that you DO NOT take anti-inflammatory tablets e.g., ibuprofen (Nurofen®), diclofenac (Voltarol®) unless advised by the hospital.

**Aspirin**

Low dose aspirin (75mg once daily) is taken to prevent the formation of blood clots. It can irritate the stomach so should be taken after food.
Medication Record Card
You will be given a Medication Record Card with details of which medicines you are taking, when to take them and what they are for. You need to carry this card with you at all times and show it to any doctor, nurse, dentist or pharmacist that gives you any treatment.

Will I continue to take the medicines I was taking before my transplant?
Most of the medicine you may have taken for your liver will normally stop when you have your transplant e.g. water tablets such as spironolactone, furosemide, and vitamins etc. You may need to continue some of your current medicines, particularly if you have other long term conditions such as asthma, epilepsy, diabetes, high blood pressure etc. Talk to your doctor or pharmacist if you would like more information.

Supply of medicines after your liver transplant
You will be given one month’s supply of all your medication when you are discharged from hospital.

Arrangements will be made for the on-going prescription of your anti-rejection medications. All other medications should be obtained from your GP.

Please make an appointment to see your GP as soon as you are discharged to discuss this.

It is important to keep a careful count of your medicines. Do not wait until you have run out or are on your last tablet before ordering.
Running out of tablets is dangerous and you should arrange to collect a new prescription at least a week before you run short. Try to keep at least a two-week supply of all medicines at all times.

When your GP starts to prescribe your medicines try to use one local pharmacy so that they have a record of the medicines you are on and are likely to keep them in stock for you. When you receive your medicines from the pharmacy, check them carefully against your medicines card and if anything appears different from usual check with the pharmacist.

If you have any concerns regarding the supply of your medicines, please speak to the pharmacist/pharmacy technician in the outpatient clinic.

You may need to pay a prescription charge unless you are exempt from prescription charges. If you have to pay it may be cheaper to purchase a pre-payment certificate.

Or apply online https://www.nhsbsa.nhs.uk. There is a cost for this - please see the website for up to date prices.

What do I do if I am sick or have diarrhoea?
If you are sick more than an hour after you have taken your medicine, you should not retake them as they will have already been absorbed into your blood stream.

If you are sick within an hour of taking your medicine (and particularly if you see remains of the medicine in your vomit), take the tablets again later when you are feeling better.
If you are not sure, do not retake your tablets and take your next dose as normal.

**Is it safe to have vaccinations after a liver transplant?**

If you need a vaccination after your liver transplant, it is important to check it is safe for you to have.

Vaccines work to give you immunity to a disease by having a small amount of the bugs that cause the disease injected into your body. Your body mounts an immune response to kill the bugs. You should become immune to the disease because if you come into contact with the disease your body will recognise it and fight it straight away.

**Types of vaccine:**

- Live.
- Inactivated or ‘dead’.

Live vaccines have a tiny amount of the live bugs in them. While on immunosuppressants, your body’s immune system will not respond as well and there is a possibility you could get the infection from the vaccine. **It is very important that you do not have any live vaccinations after your liver transplant.**

Inactivated or dead vaccines are safe to have after a transplant, and you cannot get the infection from the vaccination.

If you need to receive any vaccinations you must check with your doctor that they are not live.
**Live vaccines - NOT SAFE to have after a liver transplant**

- Oral Polio.
- Oral Typhoid (Ty21a).
- BCG (Tuberculosis).
- Yellow Fever.
- Varicella Zoster (Varilrix, Varilvax).
- Measles/Mumps/Rubella (Priorix, MMRVaxPro).
- Influenza nasal (Fluenz Tetra).
- Rotavirus (Rotarix).
- Shingles (Zostavax).
- Smallpox (Vaccinia).

**Inactivated vaccines - SAFE to have after a liver transplant**

- Inactive Polio Vaccine (IPV- injection).
- Typhoid injection.
- Hepatitis A.
- Hepatitis B.
- Influenza (Flu jab).
- Pneumococcal.
- Meningococcal A, B and C.
- Diptheria/Tetanus/Pertusis (combined vaccines).
- Haemophilus influenza B (HIB).
- Rabies.
- Japanese encephalitis.
All immunosuppressed patients are advised to have an annual influenza vaccination and a pneumococcal vaccine every five years.

It is usually advised that vaccinations are not given in the first six months after transplant as your response to them may be lessened.

If you are going on holiday abroad and need advice regarding vaccinations or anti-malarial tablets, please discuss with your GP or pharmacist.

**Storing your medicines**

- Most tablets or capsules are now supplied in blister packs which help to keep the drug in perfect condition until you take them. It is important not to remove the medicine out from the blister pack until you are ready to take it.

- Keep your medicines in a place that is dry and dark and neither too hot nor cold. Do not store a medicine in the refrigerator unless it is specifically labelled with instruction to do so.

- If you are no longer taking a medicine, take it to your pharmacy where it can be safely disposed of.

- Store your medicines safely out of reach of children.

**Do I need to take any antibiotics if I am having dental work done after my transplant?**

Unless you have another condition that requires you to have antibiotics before having dental work, you do not need to have antibiotics. The fact that you are on immunosuppressants alone does not mean you need antibiotics.
If any antibiotics are needed after the procedure, make sure a group of antibiotics called macrolides e.g. erythromycin and clarithromycin are avoided.

**Can I take over-the-counter (OTC) medicines?**

Never take any medicines without discussing it with your pharmacist or doctor. This includes all non-prescription medicines used to treat such common symptoms as headache, pain, heartburn, cough, a runny or stuffed nose, diarrhoea or constipation. This is because many medicines can interact with your anti-rejection drugs and either increase or reduce the levels of drug in your body. Always check with your pharmacist if the medicine will interact with any of the drugs listed on your medicines record card.

**Can I use alternative medicines after a liver transplant?**

*We DO NOT advise use of any alternative medicines as the effects on your medicines and new liver are often not known.*

Alternative medicines are thought of as “natural” medicines and are often marketed as being “safe”. There are different types of alternative medicines e.g. herbal medicines, aromatherapy and homeopathy. Alternative medicines do not go through the same testing as conventional medicines therefore little is known about some of them until they are used by people. Some herbal medicines have been found to cause problems with the liver or interact with immunosuppressants. **For this reason, it is very important that you do not take certain ones e.g Kava Kava, St Johns Wort or Echinacea.** If you are considering starting to take an alternative medicine, please discuss it with your hepatologist first.
Fasting

If you wish to fast following your transplant, please discuss it with your medical team first. You will also need to discuss if it is safe for you to alter the timing of your anti-rejection medications to fit in with your fasting.

Remember

- Only your transplant team should make changes to your immunosuppressant medication.
- Always take the same brand of tacrolimus or ciclosporin that your transplant team has started you on, do not switch between brands.
- Do not take your tacrolimus/ciclosporin or sirolimus dose the morning before clinic.
- It is very important to check with your transplant team before you start taking any new medicines or herbal preparations.
- Immunosuppressants make your immune system weaker so be extra careful with your own hygiene and being around others.

If you get side effects from your medication DO NOT STOP TAKING YOUR MEDICATION without discussing it with the medical team

Travel tips post liver transplant

Now that you have a new liver, getting back to a “normal” and healthy lifestyle is the next step. Once your medical condition is stable, there is nothing to stop you going on holiday.
**When can I travel after my liver transplant?**

- If you are travelling to Europe you can make plans to travel 6 months after your transplant.
- If you plan to travel outside of Europe, we would advise you wait for a year.
- Always discuss your travel plans with the transplant team prior to making firm and potentially expensive arrangements.
- Some destinations will require you to be vaccinated against certain diseases; check well in advance which vaccinations are required. Your GP/practice nurse will be able to provide the appropriate information on vaccines and immunisations for the area you plan to visit.
- Please see page 29 for list of vaccinations.
- Your GP, practice nurse or pharmacist can advise you if you need malaria prevention if you are planning to go to a country where there is malaria.
- Some anti-malarial treatments can affect the levels of immunosuppression in your blood so please discuss this with your transplant doctor or pharmacist if necessary.

**Should I bring a “travel letter” when I travel abroad?**

- We would recommend you take your last clinic letter with you.
- This letter will contain important information about your transplant. It will include a list of medications, some relevant recent blood results and the name of a consultant Hepatologist.
- Please request a copy of your clinic letter when you are seen in clinic. If you do not receive this please contact the Consultant’s secretary.
What should I do about travel insurance?

- We strongly advise you to take out health insurance when travelling abroad.
- 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.
- Contact the patient support group for a list of transplant friendly insurance companies. [www.stjamesltsg.org](http://www.stjamesltsg.org)

What precautions should I take when on holiday?

- Before you leave, check where the nearest hospital and/or transplant centre is in case of emergency.
- Ensure you have plenty of medication in case of unexpected delays.
- Keep half your medication in your carry on luggage in case your case goes missing.
- Store your medication at the temperature stated on the packaging (usually below 25 degrees centigrade).
- Check if the accommodation you are staying in has a fridge to store any medication that may require refrigeration (e.g Insulin).
- Avoid sun exposure when sun rays are strongest between 10am and 4pm. Always use sunscreen (SPF 50). Apply this to all exposed areas of your skin, wear sunglasses, protective clothing and a wide brimmed hat.
• Avoid swimming in stagnant water, to avoid bacteria or parasites that might make you very sick. Wear proper footwear in wet areas as some parasites enter your body through the skin on your feet.

• Use insect repellent to avoid mosquito bites.

• Ensure your accommodation has high standards of cleanliness.

• If you travel to a country in a different time zone, speak with the transplant pharmacist about how to adjust your medication schedule. Generally you should stick to local timings when taking your medication.

• Drink fizzy bottled water in areas where sanitation is of concern.
Section 4 - Dietary recommendations

Dietary recommendations following a liver transplant
A dietitian will see you regularly during your time in hospital. This is to ensure you get the correct nutrition to help your wound to heal and help you recover from your operation.

Your dietitian may have advised you take some prescribed oral nutritional supplements to boost your dietary intake. It is important to take these every day for as long as you are advised.

Once you are discharged from hospital a dietitian will see you in the post transplant clinic as needed. After 3 months we hope that you are eating normally and back to a healthy stable weight. Once your wound has healed oral nutritional supplements are usually stopped.

Food safety advice following your liver transplant

Why do I need advice on what to eat?
Following your liver transplant your immune system becomes weakened due to your immunosuppression drugs. You are at a greater risk of developing food borne infections. The guidelines in this booklet will help you to lower the risk of a food borne infection, whilst having as varied a diet as possible. It also gives general advice on safe food handling and storage for all patients who are immunocompromised.

How long do I need to keep to these guidelines?
The risk of food borne infections is higher in the first 6 months following transplant. After this time, except for in the cases listed below, you can stop following this advice and go back to eating a normal diet.
However, it will still be important to avoid undercooked pork and shellfish for life, as these foods carry an increased risk of transmitting Hepatitis E, an infection that affects the liver.

Reasons to continue/reinstate food safety advice:

• If you are taking a higher dose of steroids (more than 10mg daily of Prednisolone)

• If you are on 4 immunosuppressive medications (as listed on page 14 of this book)

If you are unsure about whether you should be following food safety advice please speak to your dietitian or one of the Hepatologists.

**Food safety - general advice**

**Shopping**

• Avoid buying food with damaged or broken packaging.

• Check all use by dates on packaging.

• Transport chilled and frozen foods home as quickly as possible. Use an insulated container or cool bag to help keep food at the correct temperature.

• Pack raw meats, poultry, and fish in a separate carrier bag to other foodstuffs: remember the packaging may be contaminated.

• Avoid buying foods like meat and cheese from open deli counters, sweets and chocolates from pick and mix stalls.

**Food preparation**

• Always wash your hands with warm soapy water before handling and preparing any foods.
• Wash your hands after going to the toilet, sneezing and after touching any pets, hair, dirty washing, rubbish or raw foods.

• Use a separate towel or use kitchen paper to dry hands. Do not use a tea towel.

• Cover any cuts and grazes with a waterproof plaster.

• Avoid preparing food if you have been unwell with food related sickness and/or diarrhoea until at least 48 hours after symptoms have passed.

• Wash salad, vegetables or fruit (if eaten with the skin on) thoroughly.

• Avoid washing poultry under the tap as this can spread bacteria over the sink and work surfaces. Leave unwashed.

**Storage**

• Check fridge temperature. Fridges should be between 0°C and 5°C.

• Store cooked foods at the top of the fridge.

• Store raw or defrosting food at the bottom of the fridge in a covered container to stop it dripping or leaking out into the fridge.

• Use and store food following the manufacturer’s instructions. Use within best before or use by dates.

• Keep eggs in the fridge.

• Check your freezer temperature. It should be below -18°C.

• Do not refreeze thawed foods.

• If food is frozen at home, label and date when put in the freezer and use within freezer star guideline on packet or inside door of the freezer.
**Kitchen hygiene**

- Keep the kitchen clean.
- Use a food safe sanitiser or disinfectant on food contact surfaces and hand contact surfaces (e.g. microwave handles, fridge door handles, taps.)
- Make sure any cloths or sponges are regularly bleached, disinfected or changed.
- Keep pets away from work surfaces, food and your dishes.
- Avoid cross-contamination of food by changing or washing chopping boards and utensils between raw and cooked foods. Ideally you should have three plastic boards; one for raw meat, one for cooked meat and one for other foods.

**Cooking**

- Thaw meat and poultry in the fridge and not at room temperature, as bacteria can grow more quickly at room temperature.
- Always cook raw foods thoroughly and ensure the food is piping hot all the way through, juices running clear and with no pink showing.
- Always follow the manufacturer’s cooking guidelines and do not shorten cooking times.
- Pre-heat the oven to make sure food is cooked at the recommended temperature.
Reheating foods
• Do not reheat cooked rice.
• For home cooked foods, cover and cool food at room temperature within an hour after cooking and then place in the fridge or freezer.
• Eat reheated food within 24 hours of preparing or defrosting it. Only reheat once.

Eating out
• Use reliable/reputable outlets.
• Avoid eating from street vendors and market stalls.

Higher and Lower risk foods
The following table shows foods have been divided into 2 categories;

Lower risk foods: foods which are considered safer to eat as long as they have been stored, handled and served appropriately.

Higher risk foods: Foods with which there is a higher risk of infection and therefore to be avoided.
## Meat and Poultry

<table>
<thead>
<tr>
<th>Higher Risk foods</th>
<th>Lower Risk foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw or undercooked meat and poultry.</td>
<td>Well cooked meat and poultry. Juices must run clear and no pink showing.</td>
</tr>
<tr>
<td>Barbecued meat represents a particularly high risk and is best avoided altogether.</td>
<td></td>
</tr>
<tr>
<td>Cooked meat from the deli counter</td>
<td>Vacuum packed sliced meat, check use by dates and eat within manufacturers guidelines once opened.</td>
</tr>
<tr>
<td>Salami</td>
<td>Well cooked sausages and burgers cooked in an oven or grill.</td>
</tr>
<tr>
<td>pâte</td>
<td>Hot dogs sausages re-heated thoroughly.</td>
</tr>
<tr>
<td></td>
<td>Tinned meat/meat paste. Once opened transfer to an airtight container, label, date and keep in the fridge. Eat within the manufacturer’s guidelines.</td>
</tr>
</tbody>
</table>

## Fish

<table>
<thead>
<tr>
<th>Higher Risk foods</th>
<th>Lower Risk foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shellfish e.g. prawns, mussels and any products containing them.</td>
<td>Freshly cooked fish, fishcakes, fish-fingers.</td>
</tr>
<tr>
<td>Fish Pâte</td>
<td></td>
</tr>
<tr>
<td>Raw fish e.g. Sushi</td>
<td>Tinned fish, tinned fish paste</td>
</tr>
<tr>
<td>Higher Risk foods</td>
<td>Lower Risk foods</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Smoked fish e.g. salmon</td>
<td>Frozen fish thoroughly defrosted and well cooked</td>
</tr>
<tr>
<td>Vacuum packed fish</td>
<td>Cooked dishes containing smoked fish</td>
</tr>
<tr>
<td>Dairy products</td>
<td></td>
</tr>
<tr>
<td><strong>Higher Risk foods</strong></td>
<td><strong>Lower Risk foods</strong></td>
</tr>
<tr>
<td>Unpasteurised milk.</td>
<td>Pasteurised milk, UHT milk, sterilised milk.</td>
</tr>
<tr>
<td>Unpasteurised cream.</td>
<td>Pasteurised cream. Sterilised, UHT or Squirty cream.</td>
</tr>
<tr>
<td>Soft cheeses e.g. Brie, Camembert.</td>
<td>Vacuum packed hard cheese e.g. cheddar, edam, Red Leicester.</td>
</tr>
<tr>
<td>Unpasteurised cheese - Feta, Parmesan, goat’s cheese.</td>
<td>Processed cheese e.g. Kraft slices, Dairylea triangles, Cheese strings.</td>
</tr>
<tr>
<td>Blue veined cheese e.g. Stilton, Danish Blue.</td>
<td>Cream cheese e.g. Philadelphia</td>
</tr>
<tr>
<td>Salad dressings containing blue cheese</td>
<td>Pasteurised cheese e.g. Parmesan, Mozzarella</td>
</tr>
<tr>
<td>Yoghurt which is described on the label as bio or probiotic*.</td>
<td>Any yoghurt that does not describe itself as bio or probiotic including live, plain, Greek and fruit yoghurts.</td>
</tr>
<tr>
<td>Probiotic or “bio” foods, drinks or supplements e.g. Yakult, Actimel, Proviva.</td>
<td></td>
</tr>
</tbody>
</table>

* The live bacteria used in making yoghurts are not harmful. So yoghurt described as “live” is safe.

| Soft whip ice cream from ice cream vans and ice cream machines                  | Wrapped individual ice cream or lollies. Small individual tubs of ice cream where possible. |
### Eggs

<table>
<thead>
<tr>
<th>Higher Risk foods</th>
<th>Lower Risk foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non UK eggs.</td>
<td>Use only Lion code stamped eggs or those bought from a farmer who has a certificate to show the hens are Salmonella free. These eggs can be cooked, lightly cooked or raw.</td>
</tr>
<tr>
<td>Hen eggs without the Lion code stamp.</td>
<td></td>
</tr>
<tr>
<td>Eggs not from hens e.g. duck eggs, quail eggs.</td>
<td></td>
</tr>
</tbody>
</table>

### Salad, Fruit and Vegetables

<table>
<thead>
<tr>
<th>Higher Risk foods</th>
<th>Lower Risk foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid pre-packed salads/deli counter salads.</td>
<td>All other salad vegetables are safe to eat as long as they are well washed.</td>
</tr>
<tr>
<td>Avoid pre packed chopped fruit and vegetables.</td>
<td>Peel fruit or vegetables where possible.</td>
</tr>
<tr>
<td>Avoid damaged or bruised fruit.</td>
<td>Buy bags of fruit e.g. apples as these won’t have been handled as much.</td>
</tr>
<tr>
<td>Avoid rice salads.</td>
<td>Thoroughly cooked sprouted seeds.</td>
</tr>
<tr>
<td>Raw sprouted seeds i.e. alfalfa, bean.</td>
<td>Wash well all fruit and vegetables in freshly run water.</td>
</tr>
<tr>
<td>Unwashed or unpeeled raw fruit and vegetables.</td>
<td>Pasteurised fruit juice or smoothies.</td>
</tr>
<tr>
<td>Unpasteurised fruit juice or smoothies.</td>
<td></td>
</tr>
</tbody>
</table>
**Water**

<table>
<thead>
<tr>
<th>Higher Risk foods</th>
<th>Lower Risk foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid still bottled mineral water.</td>
<td>Carbonated bottled water.</td>
</tr>
<tr>
<td>Un boiled water that is not from local authority supply.</td>
<td>Freshly drawn tap water.</td>
</tr>
<tr>
<td>Holy water.</td>
<td>If you drink water from a borehole or private water supply this must be boiled prior to drinking.</td>
</tr>
<tr>
<td>Home filtered water e.g. From water filter jug or American style fridge with water supply.</td>
<td><em>Listen to any advice from health/local authority re: needing to boil your water supply. Ensure you run your water for a couple of minutes first and that it is a tap that is regularly used.</em></td>
</tr>
</tbody>
</table>

More information on safer shopping and eating can be found at: [www.food.gov.uk/safereating](http://www.food.gov.uk/safereating)

**Potassium**

Some of your immunosuppressive drugs can make you retain potassium. This can be dangerous as it can affect the way the heart beats.

If a high potassium level is detected in your blood you may be asked to avoid foods that contain a lot of potassium. **If a doctor or dietitian has advised you to follow this advice please see Appendix 1.** Your potassium will be checked regularly and you will be advised when you can stop the low potassium diet.
Healthy eating advice following your liver transplant

If you were overweight before your liver transplant, once you are fully recovered from your transplant discuss your weight with your dietitian. Give yourself a target healthy weight for your height. Excess weight can lead to long term health problems such as high blood pressure, heart disease and diabetes. If you require any information regarding healthy eating please speak to your dietitian. (See Appendix 2)
Section 5 - General Health

Alcohol

If alcohol has caused or made a contribution to your liver disease, you will have already met the alcohol team and have been asked to sign an agreement that you will never drink alcohol again.

It is very important that you continue to comply with this after your transplant for a number of reasons.

- The medication that you need to take after your transplant to stop your body rejecting your new liver may make it more difficult for your liver to break down the alcohol, so relatively small amounts can damage it quite quickly.

- It is possible that if you have drunk too much in the past, you may be unable to stick to low levels of alcohol use and you may find that you return to drinking at potentially harmful levels very quickly.

- Sometimes when people start to drink again they may find that they are not keeping their appointments, looking after themselves, or taking their medication properly. This could have a harmful effect on your new liver.

It is also very important that you continue to avoid alcohol in food and that you do not use products such as mouthwashes that contain alcohol. You should also continue to avoid ‘alcohol free’ beers, wines and ciders, as we know that people who drink these types of products are more likely to return to drinking and are also at much higher risk of consuming alcohol by mistake.
If you are having thoughts about drinking, or you are concerned that you may drink, the alcohol team are available for you to contact for support and advice, even if it is many years after you had your transplant.

**What about drinking alcohol after a transplant if it was not a factor in your liver disease?**

Drinking alcohol after a liver transplant, whatever the underlying liver disease is **NOT** recommended, as having to break down alcohol causes extra strain on your liver, which is best avoided. This is particularly important in conditions that may recur after transplantation, such as viral hepatitis and NAFLD (non-alcoholic fatty liver disease). Asking your liver to break down alcohol can speed up and exacerbate the damage caused by the underlying condition. Medication given to prevent your body from rejecting your new liver also makes it more difficult for it to break down the alcohol.

If you do decide that you wish to drink alcohol after your transplant, it should be only very occasionally and no more than one or two units (a small glass of wine or a pint of 4% lager) on any occasion.

**Please ask to speak to the alcohol team if you have any questions about this.**

**Illicit drugs**

It is important that you avoid taking any illicit substance after your transplant, as these could have unpredictable consequences. They may interact with your prescribed medication, possibly leading to damage in your new liver. If you have any concerns or questions about this, please speak to the specialist misuse nurse.
Dental care
After your transplant, you should continue your regular dental check-ups as frequently as your dentist recommends.

- Do tell your dentist that you have had a transplant and that you are taking anti-rejection therapy.
- Take your medicine card along with you in order that your dentist can see exactly what you have been prescribed.
- Keep your teeth clean by brushing twice daily and maintain your usual dental hygiene.

Driving
This depends upon your individual recovery. Before you resume driving please discuss this with the medical team in clinic. You may be ready to consider returning to driving 2-3 months after your transplant.

It may be worth informing your car insurance company that you have had a liver transplant and are not able to drive for a short period of time following your transplant.

Exercise
After any surgery early mobilisation and breathing exercises help keep your lungs clear and prevent muscles weakening. The physiotherapist will teach you deep breathing exercises to perform yourself, on an hourly basis after surgery. They will also show you toe, foot and ankle exercises to help with circulation and muscle strength until you start walking normally. After your transplant it is important to remain active, initially you may not feel strong enough to exercise for long periods of time. The physiotherapist will help you find the right level of activity following your operation.
Physical activity can improve your energy levels, aid sleep, improve muscle and body tone, reduce stress and can reduce some of the effects of steroids.

Initially the abdominal muscles are weak post transplant and could be at a greater risk of developing hernias.

We advise that for the first THREE months you AVOID:

• Heavy Lifting (greater than 15lbs).
• Strenuous Abdominal Exercises.
• Heavy Housework and DIY.
• Gardening.
• Swimming (the wound needs to be fully healed).
• Contacts Sports (eg. rugby, football).

There is no reason why a patient having had a transplant should not return to all sporting activities and doing the activities you enjoy, let your body recover from the surgery first.

Walking

• Walking is one of the best forms of exercise!

Build up slowly, start with 10 - 15 mins and build up every two to three days. The distance you achieve will depend on your age and condition of your health before your transplant.
Always remember, if you have: Chest Pain, Leg Pain or Shortness of Breath, Dizziness or Light Headedness - STOP and REST! You have probably done too much too soon.

Yoga and Pilates are gentle forms of exercise that will help build up abdominal strength and may aid relaxation. This form of exercise may be a good starting point if you have not done much activity prior to your transplant. Tell your instructor about your transplant before starting. Some GP practices have access to reduced prices at gyms, sport and leisure centres for patients post-transplant. It may be worth asking your GP if they participate in any schemes locally.
Eventually you could work towards supporting your team at the transplant games! The transplant co-ordinator will have details.

The Leeds Adult Transplant Sport Team
A supportive community for transplant recipients, their family and friends

The Leeds Adult Transplant Sport Team helps a wide range of transplant recipients to take part in sport, build friendships and celebrate the gift of life. It is a network of inspiring, resourceful and courageous people ranging from 18 to 81 years of age who take part in a variety of sports (for fun and for competition), social activities, fundraising and charity events.

We have raised over £15,000 so far to support the team and its activities, including buying new kit and equipment.

The British Transplant Games have been hosted annually since 1978, and have visited 17 host cities around the UK including Portsmouth, Newcastle, Edinburgh, Belfast and Sheffield.

The Games aim to encourage transplant patients to regain fitness, whilst increasing public awareness of the need for more people to join the NHS Organ Donation Register and discuss their wishes with their families.

The Leeds Team has been competing since 1987. In 2015 the team consisted of 40 competitors and spectators and currently has over 70 active team members and supporters - one of the largest teams at the Games.

Although only transplant recipients can compete in the Games, anyone can join the team in a support role.

We’d love you to join the team and help us grow

The Leeds Adult Transplant Sport Team welcomes anyone who lives in or has had a transplant in Leeds, their family, friends, donor families and anyone who wants to help raise awareness of organ donation.

Whether you’re interested in sport, or just want to come along and support us, there’s something for everyone to get involved with.

For more information, please contact Anokh Goodman, Team Manager:
leedsadulttransplantsport@gmail.com       0113 206 5897 / 07827 807180
www.leedsadultteam.co.uk          leedsadulttransplantsport

Returning to work
It is important for you to return to work, however recovery time is different for everyone. Depending on the nature of work, people are usually ready to return to work within 3 - 6 months after the transplant. It is important that you discuss this with the transplant doctors in clinic before returning to work. It is also important when returning to work you ensure you have a phased return.
Infections
Because of your physical condition and the medicines you need to take, you are prone to infection. Infections can be viral, bacterial or fungal.

You are most likely to pick up an infection in the first few months after transplant when doses of immunosuppressants are higher, but it would be sensible to be aware of infection risks in the long term.

How to avoid infection
• Have a flu vaccination each year and pneumococcal vaccine every 5 years
• Avoid close contact with anyone who has an infection, from the common cold to chicken pox.
• Keep good standards of hygiene - wash your hands after going to the toilet or gardening or cleaning up after pets.

If you get any of the following please contact your GP or the Liver Recipient Coordinator or Post Transplant Nurse Specialist
• Rising temperature (normal temperature 37.5°C).
  A high temperature is considered to be over 37.5°C.
• Pain, burning, difficulty passing urine.
• Sore throat, cough or cold.
• Inflamed, red or painful wound site.

Infectious diseases
If you come into direct contact with any person with an infectious disease e.g. measles, chicken pox etc. it is not considered to be dangerous if you have already had these diseases as a child.
However if you think you have not had them, contact the liver transplant co-ordinators who may advise you to have a blood test at your GP.

**Sexual activity**
You may resume sexual activity as soon as you feel well enough. Your sexual drive may be affected by transplantation as certain medications can alter sexual functioning.

How quickly you feel ready to resume sex will depend on your recovery, you may find it takes time for your sex drive to return and this is quite normal.

Due to the immunosuppression medication you will have an increased risk of sexually transmitted diseases so it is advised you practice safe sex.

**This is important for all patients and their partners.**

The use of contraception medications / implants needs to be discussed with the doctor or pharmacists before you start using them, as **NOT** all contraceptives are safe to use following your transplant.

**Women’s health**
We advise you to have a cervical smear, along with a breast examination, as there is a small increase in the risk of developing cancers when taking immunosuppressive medicines.

You should examine your breasts every month. Ask your doctor how to do this correctly, reporting anything unusual.
Menstruation will probably return to normal after your transplant, with the possibility of pregnancy as your general health improves. If you wish, you can discuss suitable contraception with one of the doctors in clinic.

Should you be contemplating pregnancy we advise careful counselling prior to conception. This is to ensure the safety of yourself and your baby.

**Men’s health**

As your general health improves your fertility and sex drive will also probably return so care must be taken to avoid unwanted pregnancies. Some men may have had trouble achieving or maintaining an erection prior to the transplant. This can continue after transplant and it is important that you discuss this with your doctor as treatment options are available.

You should examine your testicles regularly every month. Ask your doctor how to do this correctly and report anything unusual.

**Pets**

Cats and dogs are safe if they are in good health and have had all the recommended vaccinations and worm medicines. Handle litter trays with gloves and wash hands afterwards.

**Smoking**

You should not smoke before or after a transplant.

- Smoking causes lung damage leading to chest infections which can be life threatening. Smoking also causes a narrowing of the blood supply to the transplanted organ and inevitably reverses the benefits of a successful transplant. There is also an increased risk of developing mouth, throat and lung cancers.
Sunbathing and skin cancer

It is known that patients who are on immunosuppressants are more prone to skin cancer. As part of your ongoing care we recommend that you are referred to a dermatologist for an annual review.

It is therefore important that you follow these instructions;

• Do not sunbathe between the hours of 11am and 3pm.
• Sit more in the shade than in the sun.
• Wear a high factor sunscreen factor 30 or higher.
• It is important to apply this sunscreen on all exposed skin even on mildly sunny days between April and late September.
• It is also important to apply sunblock 2-3 times a day when the sun is very intense, even in England.
**Tattoos & Piercing**

Please ensure any tattoos or piercing are done by a professional artist with sterile equipment as they can transmit blood borne viruses and infections.

**Section 6 - Social Work Service**

The Liver Unit has a social worker to help you and your family with any worries or concerns you may have. You will usually have had contact with the social worker at the time of your transplant assessment.

**Travelling costs**

Certain state benefits entitle patients and families to claim help with the cost of travelling to and from hospital. Ask on the ward for further details or ask to see the social worker if you are experiencing difficulties.
Section 7 - Letter of Thanks & Support Group

Letter of Thanks

It is possible to find out some information about the person who donated their liver. Due to patient confidentiality this information is limited to the age and sex of the donor.

Likewise if a family of the donor asked for information about you they will be informed of the age and sex of the organ recipients.

We encourage you to write a letter to your donor’s family when you feel ready. The bereaved relatives gain a great deal of comfort from knowing that their loved one’s gift has saved a life. The liver transplant co-ordinator will support you and your family when writing to the donor family.

Occasionally the donor’s family may write back to you and if this is the case we will contact you by telephone to confirm if you would like to receive the letter.

The transplant co-ordinators can be contacted on telephone: 0113 206 6585 or via e mail on: leedsth-tr.livertransplant@nhs.net
The Transplant Support Group

The Support Group was set up some years ago by patients to provide support to transplant patients and their families and an opportunity for people to meet. They also give support and information to pre-transplant patients and their families. Currently the group meets every three months sharing venues between Yorkshire and Lancashire. You can still join the support group even if you can’t attend the meetings.

www.stjamesltsg.org
Who to contact if you are unwell

If it is less than 3 months after your transplant date and you have a query, please contact:

• The liver transplant co-ordinators during office hours on telephone number: 0113 206 6585.

If it is more than 3 months after your transplant please contact:

• The post transplant specialist nurse during office hours on telephone number: 0113 206 8509.

For either immediate post transplant or long term post transplant OUTSIDE of working hours please contact:

• The Liver Registrar via J83 or via switchboard on telephone number: 0113 243 3144.

For any questions regarding your medication or prescription please contact the pharmacy team directly:

• Pharmacy telephone numbers: 0113 206 6826 or 0113 206 5377.
Contact names and telephone numbers for the Liver Transplant Unit

- St James’s Hospital Switchboard
  Telephone number: 0113 24 33144

- Liver Transplant Unit (J83)
  Telephone number: 0113 20 69183 or 0113 20 68283

- Liver Transplant Coordinator
  Telephone number: 0113 20 66585.
  This is an answer machine manned between 8am and 5pm - please leave a message. If your call is urgent please contact your GP

- Intensive Care Unit
  Telephone number: 0113 20 69154

- Social Worker
  Telephone number: 0113 20 65454

- Dietician
  Telephone number: 0113 20 65868

- Outpatient Enquiries
  Telephone number: 0113 20 60606

- Substance Misuse Nurse Specialist
  Telephone number: 0113 206 6315

- Appointments
  Telephone number: 0113 206 4478

- Bexley Wing Hotel
  Telephone number: 0113 206 7687
Useful websites

PBC foundation
• www.pbcfoundation.org.uk
  The PBC foundation is a charity offering support and information to PBC sufferers, their families and friends.

Organ donation
• www.organdonation.nhs.uk
  Information about organ donation and transplantation.

British Liver Trust
• www.britishlivertrust.org.uk
  Information regarding all aspects of liver disease and transplantation.

Liver Transplant Support Group
• www.stjamesltsg.org
  Support group founded by liver transplant recipients and their families.
Appendix 1

Low Potassium Diet

Only follow this advice if a doctor or dietitian has advised you to do so.

Your potassium will be checked regularly and you will be advised when you can stop the low potassium diet.

- Only have two small servings of vegetables a day; two tablespoons equals one serving.

- A small portion of salad may be used in place of one serving of vegetables. This may contain lettuce, cucumber, spring onion, pepper, radish and one small tomato (N.B. pickled onion and beetroot may be added in small amounts).

- Always boil your vegetables well, in plenty of water and discard the cooking water. Do not drink it or use it for making gravy, soups or stocks.

- Avoid using a pressure cooker or microwave when cooking vegetables.

- After boiling, potatoes can be chipped or roasted but not more than twice a week.

- Limit your fruit to two portions per day. One portion of fruit is an apple or pear or a small bowl of tinned fruit e.g. two peach halves.
• Rice, pasta and bread are low in potassium. They are suitable alternatives to potatoes. Yam, sweet potato or plantain can be eaten instead of potatoes if boiled well and are of a similar portion size.

• Until your diet is assessed by your dietitian, please continue with your current portion sizes of meat, fish, quorn, tofu, cheese, eggs and yogurt.

• If you are vegetarian you may continue to eat pulses and lentils.
<table>
<thead>
<tr>
<th>Foods to Avoid which are High in Potassium</th>
<th>Suitable Alternatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Potatoes</strong></td>
<td>Boiled or mashed potatoes; up to 3 small potatoes a day. Boiled rice, boiled pasta e.g. macaroni and spaghetti. Bread (all types), chapattis, plain naan, pitta and crumpets.</td>
</tr>
<tr>
<td>Fried, oven, microwave or frozen chips, instant mashed potato, jacket potatoes, potato waffles and potato croquettes.</td>
<td></td>
</tr>
<tr>
<td><strong>Vegetables</strong></td>
<td>French or green beans, carrots, broccoli, cabbage, cauliflower, leeks, swede, sweetcorn, onions, peas, pepper, mange tout, beansprouts, courgette, celery, mixed vegetables, 1 small tomato a day, lettuce and cucumber.</td>
</tr>
<tr>
<td>Baked beans, butter beans, chick peas, lentils, red kidney beans, haricot beans, mung beans, spinach, mushrooms, tinned tomatoes, tomato puree, sprouts and parsnips.</td>
<td></td>
</tr>
<tr>
<td><strong>Fruit</strong></td>
<td>Apples, pear, peach, small orange, pineapple, strawberries, raspberries, kiwi fruit, lemon, mandarin, small nectarine, plum, tangerine, satsuma and tinned fruit in syrup.</td>
</tr>
<tr>
<td>Apricots, banana, damsons, rhubarb, cantaloupe melon, blackberries, redcurrants, blackcurrants, grapes, avocado, cherries, starfruit and dried fruit e.g. raisins.</td>
<td></td>
</tr>
<tr>
<td><strong>Drinks</strong></td>
<td>Water, tea, orange or lemon squash, lemonade, cola drinks, 7-up, Tango, Sprite, Lilt, soda and tonic water, spirits and dry white wine.</td>
</tr>
<tr>
<td>Coffee, cocoa, fruit juice, blackcurrant squash, Horlicks, Ovaltine, Bournvita, stout, red wine, cider, barley wine, liqueurs, red wine, sweet white wine and sweet sherry. Limit your milk intake to ½ pint (200mls) per day.</td>
<td><em>If diabetic, choose light, diet and no-added sugar options</em>.</td>
</tr>
<tr>
<td>Foods to Avoid which are High in Potassium</td>
<td>Suitable Alternatives</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td><strong>Snacks</strong></td>
<td></td>
</tr>
<tr>
<td>Potato crisps, nuts, chocolate, liquorice, fudge, marzipan, peanut butter, cakes and biscuits containing chocolate, coconut, coffee and dried fruit.</td>
<td>Maize snacks e.g. Skips, Monster Munch, Wotsits, sweets, mints, chewing gum.</td>
</tr>
<tr>
<td></td>
<td>Plain and cream cakes, plain biscuits and jelly.</td>
</tr>
<tr>
<td><strong>Cereals</strong></td>
<td></td>
</tr>
<tr>
<td>Any containing dried fruit and nuts, All Bran, muesli, Fruit &amp; Fibre, Sultana Bran, Ready Brek, Nutrigrain, Weetaflake ‘n’ Raisin, Weetos oatcakes and rye crispbread.</td>
<td>Porridge, cornflakes, Weetabix, Rice Krispies, Cheerios, Sugar Puffs, Shredded Wheat, Shreddies, Special K and Frosties.</td>
</tr>
<tr>
<td></td>
<td>Cream Crackers.</td>
</tr>
<tr>
<td><strong>Miscellaneous</strong></td>
<td></td>
</tr>
<tr>
<td>Spaghetti in tomato sauce.</td>
<td>Vinegar, pepper, herbs and spices.</td>
</tr>
<tr>
<td>Tomato sauce - limit to 1 teaspoon only.</td>
<td></td>
</tr>
<tr>
<td>Curry powder and Lo Salt.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2

Each serving (150g) contains
of an adult’s reference intake
Typical values (as sold) per 100g: 697kJ/ 167kcal

Check the label on packaged foods

Energy
Fat
Saturates
Sugars
Salt

Choose foods lower in fat, salt and sugars

Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat. Eat no more than 2 portions of processed meat per week.

Eat less often and in small amounts

Eat more fruit and vegetables

It shows how much of your total should come from each food group.

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food.

Eat well on


Eatwell Guide

Per day 2000kcal

Eat all food + all drinks

Choose unsaturated oils

Oil & spreads

Eat at least 5 portions of a variety of fruit and vegetables every day

Fruit and vegetables

Choose wholegrain or higher fibre versions with less added fat, salt and sugar

Potatoes, bread, rice, pasta and other starchy carbohydrates

Choose lower fat and lower sugar options

Dairy and alternatives

Eat less red and processed meat.

Beans, pulses, fish, eggs, meat and other proteins

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