

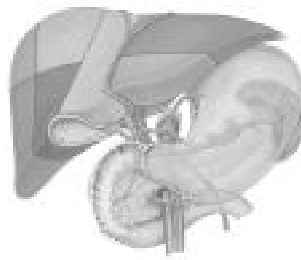
We are delighted that you have been able to receive a transplant and are now able to recover. This booklet gives you advice on living with your transplant, how to avoid problems and how to make the most of your new lease of life.

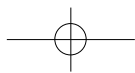
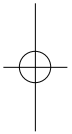
We have tried to answer many of the common questions which patients ask. However, if you have any other questions, no matter how silly they may seem, do ask us and we will try to help.

We have provided 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.

Division of Liver Services September 2006





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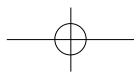
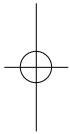
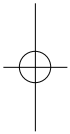
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SECTION 1

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 & 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- 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- 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. 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

Patients' Experience

This section focuses upon the patients' experience of liver transplant. It is a collaboration of different individual's accounts and has been amalgamated to provide a diverse understanding of liver transplant.

Waiting for the call was a common theme described by patients, with telephone, mobile and pager always within easy reach day or night. One patient details his continual checking of the batteries and replacing them even though they were alright but "just in case" as well as testing the pager to ensure it works. In addition an overnight bag was packed and ready for the call. To summarise, waiting for the vital call can take over your life with emotions ranging from anticipation in waiting, anxiety in not receiving the call to overwhelming relief and gratitude when the call is made. One patient describes the shock he felt at getting the call as he had not waited a long time and while he was not sure he felt prepared but he believes it would not have made a difference regardless of timeframe.

Going to theatre is understandably an anxious time for yourself and your relatives. You will be escorted, along with your family, to theatre by a member of nursing staff from the liver unit. The liver transplant takes between 6 to 12 hours to perform. During this time your family can either go home or wait in the flat, which belongs to the liver unit opposite the hospital. Unfortunately there is no waiting area around ward 71. We appreciate this is an anxious time for your family but ask you not to ring the liver unit to ask for an update of the operation as the nurses do not get any information once the patient has left the ward. It is best to ring the intensive care unit (ICU), as they will be the first to receive news on the patients expected time of arrival on to the unit. It is expected that you will spend only a few days in the ICU where you will be constantly monitored during the critical stage of your recovery.

Transfer to the liver unit from the intensive care unit will occur once you are stable post operation. When you return to the liver unit you will be connected to lots of machines. These will be monitoring fluids and medications to aid your recovery. Don't be frightened to ask any questions and you will be surprised how quickly they disappear!

Once back on the ward you will start to slowly 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 may be a concern to patient's undergoing transplantation. You will receive morphine in a drip to ease the pain. Don't worry about the pain; it is normal to feel discomfort around the wound. Discomfort rather than pain around the area where the drains are or were once housed. This feeling of a 'stinging' or 'pulling' sensation can be quite severe at times, but it is nothing to worry about. During the healing process parts of the internal muscles stick together and instead of moving around freely, they pull hence the discomfort. One patient advises to relax and to take painkillers even if you don't have pain but only in the early days after transplant.

Constipation can be a problem, but eating a high fibre diet can reduce this. There will also be discomfort around the abdominal area. Wind pain from the surgery is obvious but it does lessen as time passes. Distension (swelling) of the tummy is also evident but once again reduces over a period of time. It is a matter of acceptance, as a positive attitude really does help to contribute towards healing.

Recovering from the operation is different for each patient. The most important aspect, one patient described, was to take each day as it came and listen to advice given by the doctors and nurses caring for you. Slowly you will begin to feel better, but will be tired very quickly. Relax and put your feet up each day. Don't compare yourself to other patients' who may be at a similar stage as other people may seem to be recovering quicker, which will make you feel frustrated. Concentrate upon the positive aspects, you are alive and on the road to recovery.

One patient describes that the hope of being able to walk his girls down the aisle was his source of inspiration, which helped him recover and was a prime focus for going to theatre. Whatever your reason, try to draw upon it to remain positive.

Drugs are a vital part of the transplant process. You will be on a variety of drugs initially ranging from anti-rejection medication to antibiotics and painkillers. It is difficult to get used to the names and functions of the drugs, but the self-medication scheme on the ward is helpful. Take your time and seek assistance from the nursing staff. Eventually you will find, according to one patient, taking the medication to be an automatic and natural part of your daily routine.

The drugs do have side-effects including confusion in the immediate post operative phase. Fortunately you will have no recollection, but your family, friends and hospital staff will be able to remind you! It is not a common side effect and does not often last more than a few days. Further side-effects involve fluid retention, which makes you legs swell. Walking short distances regularly then putting you feet up will help reduce the swelling.

Going home to lead a normal life is the major benefit of transplantation. Although it is a day, which you will aim towards from the first day you go into hospital for the operation, going home can be an overwhelming experience. One patient describes the feeling of anxiety having left the safety of the hospital, whereby there is always a member of staff available to allay your fears and help you make a decision. It is at this point when you realise how much you have relied on the staff on the liver unit.

Going home also can become a catalyst for thinking about the donor family. For one patient the joy at going home was tinged with overwhelming sadness for the family who lost a loved one in order for him to be alive. For most patients' the donor family are always in their thoughts and whose gift will always be remembered.

Emergency Transplantation is rare but necessary for some patients. For one patient it happened when she was a teenager. For weeks she felt tired but put this down to the pressure of looming examinations. However when she became jaundiced she was admitted to her local

hospital, where a series of blood tests and investigations were performed before being transferred to St James' for further treatment. Within hours it became apparent that she would not survive for more than a few days without a transplant. She was placed on the emergency list and was transplanted the next day. Although the immediate pre and post operative phase was a blur, the transplant had saved but changed her life forever. Unlike other patients she had no time to prepare for transplant as she did not know she had liver failure, which means she needed to adjust to her new life. This takes time and everyone is different in how they approach and come to terms with an emergency transplant.

On a positive note, she is now at college living a normal life with a supportive family, friends and boyfriend and is accepted for who she is not as a person with a different organ.

Whether your transplant is because of a chronic disease or an acute liver failure, it may be pertinent to remember these words

“Save not your best for the future, don't wait to give your best to the next job, the next time or the next opportunity, give your best NOW!!!”

Out-patient's Clinic

Following your discharge you may be asked to come and visit the unit, to have your blood taken. However if you live very far away your follow up care can be shared between your local hospital and St James's. The clinic is held every Friday morning, in Chancellor's Wing. Initially you will be asked to come weekly then the visits will become less frequent. When you come to the unit or clinic, **please do not take your cyclosporin or tacrolimus that morning**, but bring it with you in order that you can take it as soon as your blood has been taken, because we monitor your blood levels to ensure you are getting the right amount, You must appreciate that it may not be possible to see the same doctor every week. Occasionally it is necessary 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 felt healthy, it is important to realise that it is a minor setback.

The role of the Clinical Nurse Specialist

The majority of transplant patients will already know the clinical nurse specialist as they will have monitored their health whilst on the waiting list. Post transplant the clinical nurse specialist will help with the patient education and assist in preparing both patients and relatives for discharge home. You will attend the Friday post transplant clinic regularly. Following your clinic visit we may call you to ask for more blood tests to be taken at your GP's or to adjust your medication dosage.

The clinical nurse specialists are available for help and advice on their direct telephone line (0113) 2066585. They are also available in the transplant outpatient's clinic and may help you to continue to promote your health for the future.

Who to contact if you have a problem

On your discharge home from the unit your GP will be sent a letter about your transplant and treatment. If you have a problem please contact the unit. You may then be advised to contact your GP if necessary.

Contact names and telephone numbers for the Liver Transplant Unit

Direct line	(0113)
St James's Hospital Switchboard	2433144
Liver Transplant Unit	2067184 or 2065771
Intensive Care Unit	2065890 or 2064584
Clinical Nurse Specialist	2066585
Transplant Co-ordinator	2064930 or 2064553
Social Worker	2064628
Dietician	2066628
Outpatients enquiries	2060606

Useful websites

www.pbcfoundation.org.uk

www.uktransplant.org.uk

www.britishlivertrust.org.uk

www.stjameslts.org

SECTION 3

Information About Your Medicines

Introduction

This section includes information about the medicines you will need to take after your liver transplant.

- The term “medicine” includes any tablet, capsule, liquid, inhaler or other form of medication you take. Medicines can be prescribed to you by your doctor or bought over the counter and includes herbal medicines.
- Medicines are an essential part of your treatment after your liver transplant and you will need to take at least one type of medicine every day for the rest of your life.
- 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 around with you at all times and show it to any doctor, nurse, dentist or pharmacist that gives you any treatment.
- If you are admitted to hospital (either St James’s or a local hospital) always take your current medicines with you.
- Some of the information included in this medicine section is important for you to read before your transplant. You can also use it as a resource after your transplant to answer some questions you may have in the future.

Sample Medication Card often taken following a Liver Transplant

The Leeds Teaching Hospitals
Liver Unit



NHS Trust

Medicine	Dose	06.00	10.00 B*fast	14.00 Lunch	18.00 Tea	22.00 B*time	Why am I taking it?	Additional Information
Ciclosporin (Neoral®) or Tacrolimus capsules	Depends on blood levels		✓			✓	Anti-rejection medicine. Likely to be taking for the rest of your life.	The amount of medicine in your blood is checked whilst you are in hospital and at clinic visits. Your dose will be altered according to the level in your blood. The blood sample is taken before your next dose. It is important not to take it on the morning before your clinic visits.
Azathioprine or Mycophenolate mofetil tablets	Azathioprine (Depends on weight/blood tests) Mycophenolate mofetil (dose varies)		✓			✓	Anti-rejection medicine. Likely to be taking for the rest of your life.	
Prednisolone tablets	Higher dose at first, reduced slowly		✓				Anti-rejection medicine. Also a steroid.	Not all patients are given prednisolone. If you are, it is usually reduced slowly and stopped by 3 months after the transplant.

Medicine	Dose	06.00	10.00 B*fast	14.00 Lunch	18.00 Tea	22.00 B*time	Why am I taking it?	Additional Information
Co-trimoxazole (Septrin®)	One tablet		✓				Prevent a lung infection that immunosuppressed patients can get.	For the first 3 months after the transplant.
Valganclovir tablets	Usual dose is two 450mg tablets		✓				To prevent a viral infection called "CMV"	Only given to some patients if they did not have the virus before transplant but the donor did. Only a three month course.
Paracetamol tablets	Two tablets		✓	✓	✓	✓	Pain killers. Can be taken when needed	Maximum 8 tablets a day.
Dihydrocodeine tablets	One or two tablets (30mg)		✓	✓	✓	✓	Pain killers. Can be taken when needed	It is usually wise to reduce and stop dihydrocodeine before starting to reduce paracetamol because dihydrocodeine is a stronger painkiller than paracetamol
Plus: any other medicines still needed for other conditions.								

Will I continue to take the medicines I was taking before my transplant?

The medicines you are taking for your liver will normally stop when you have your transplant eg spironolactone, frusemide and vitamins. You may need to continue taking some of your current medicines particularly if you have other conditions such as asthma, epilepsy, diabetes, high blood pressure etc. Talk to your doctor or pharmacist if you would like more information.

What types of medicine will I take after my liver transplant?

After your transplant you will take a number of different medicines for different reasons. You will be started on several different types at first but the number usually reduces over the first few months.

The main types of medicine are:

- **Anti-rejection medicines (immunosuppressants)**
- **Anti-ulcer medicines**
- **Medicines to prevent infections**
- **Pain killers**
- **Sometimes, blood pressure tablets**
- **Sometimes, blood sugar medicines**

An example of a Medication Record Card for medicines after transplant is printed overleaf. Each of the different types of medicines will be discussed over the next few pages.

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

Because immunosuppressants reduce 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 infection.

Taking immunosuppressants increases your chance of developing certain types of cancer, mainly skin cancer. Most skin cancers can be treated successfully if they are caught at an early stage.

It is important that you follow the following advice:

- Examine your body at monthly intervals. Report any unusual lumps to your doctor
- Report any changes in size, colour or shape of moles to your doctor. When exposed to strong sunlight wear a hat, long sleeved shirts and long trousers where possible. Use high factor sun cream (SPF 30), on exposed areas. Avoid the sun when it is at its strongest, between 11am and 3pm where possible.
- Despite this disadvantage of immunosuppressants, the benefits of a transplant outweigh the long term problems.
- You will normally be started on two or three immunosuppressants at first. These work together to prevent your immune system rejecting your new liver.

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

- **Ciclosporin (Neoral®) or tacrolimus (never both together)**
- **Azathioprine or mycophenolate mofetil (never both together)**
- **Prednisolone**
- **Sirolimus**

The different types of immunosuppressant 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.

Ciclosporin (Neoral®)

- You will usually be started on ciclosporin or tacrolimus. This is the strongest type of immunosuppressant and the one you will probably take for the rest of your life. Ciclosporin works by blocking the production of cells that attack the new liver.
- It is important that you take the brand of ciclosporin called Neoral®. It is important that you do not take a different brand unless advised to by St James's.
- Ciclosporin is taken twice a day, about twelve hours apart. Choose times suitable to you eg 8am and 8pm or 10am and 10pm. Swallow the capsules whole with a glass of water.
- During your hospital stay and when you visit the outpatient clinic, we will take blood samples to measure how much ciclosporin is in your blood stream. In hospital, we measure a ciclosporin level two hours after your dose. In outpatient clinic we measure a level before you take your next dose. The dose will be altered according to how much is in your blood stream. As time goes by, if your new liver is working well, we can reduce the dose.
- On clinic days, do not take your ciclosporin 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 by telephone within a few days of your clinic visit.
- **You should not eat grapefruit or drink grapefruit juice whilst you are taking ciclosporin because it contains a chemical that affects the level of ciclosporin in your blood. Other citrus fruits are safe to eat or drink.**
- Ciclosporin is available in different strengths of capsules: 25mg (blue/grey), 50mg (yellow/white) and 100mg (blue/grey).

Side effects of ciclosporin

Ciclosporin has several side effects but not everyone will experience them. Some of the side effects disappear as the dose of ciclosporin is reduced over time.

- **Tremor (shaking) of the hands**
- **Headache**
- **Vivid dreams**
- **Upset stomach**
- **Increased hair growth on body, legs and face**
- **Overgrown gums**
- **Numb, hot or tingly hands, feet or mouth**
- **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 something we can do to help. Your blood pressure and kidney function will be checked in outpatient clinic so changes can be made if needed.

Taking other medicines with ciclosporin

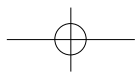
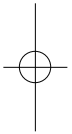
Some medicines can increase or decrease your ciclosporin level in the blood. This may either increase your chance of side effects or rejection. Always check with your doctor or pharmacist if you are prescribed or you buy any new medicines.

There are various medicines that you should not take whilst on ciclosporin, these include two antibiotics called erythromycin and clarithromycin.

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 ciclosporin

A missed dose should be taken at least six hours before the next dose is due. If there is less than six hours before your next dose, do not take the missed dose, just take the next dose at the normal time. Never take double doses to make up for missed doses.



Tacrolimus

- You will usually be started on ciclosporin or 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.
- Tacrolimus is taken twice a day, about twelve hours apart. Choose times suitable to you e.g. 8am and 8pm 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.
- The dose will be altered according to how much is in your blood stream. 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 stream.
- 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 by telephone within a few days of your clinic visit.
- **You should not eat grapefruit or drink grapefruit juice whilst you are taking tacrolimus because it contains a chemical that affects the level of ciclosporin in your blood. Other citrus fruits are safe to eat or drink.**
- Tacrolimus comes in capsules that are 0.5mg (yellow) 1mg (white) and 5mg (greyish-red).

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.

- **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 outpatient clinic so changes can be made if needed.

Your blood sugars will be tested while you are in hospital to test to see if you develop diabetes. While you are at home symptoms to watch for are feeling very thirsty and passing increasing amounts of urine. Tell the doctor in clinic if you experience these symptoms.

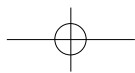
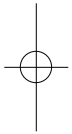
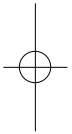
Taking other medicines with tacrolimus

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. There are various medicines that you should not take whilst on tacrolimus, these include two antibiotics called erythromycin and clarithromycin.

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 tacrolimus

A missed dose should be taken at least six hours before the next dose is due. If there is less than six hours before your next dose, do not take the missed dose, just take the next dose at the normal time. Never take double doses to make up for missed doses.



Azathioprine or Mycophenolate Mofetil

- Azathioprine or mycophenolate mofetil is the second type of immunosuppression you will usually take after a liver transplant. They act in a similar way to reduce the number of white cells in the blood which play an important role in rejection. 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 25mg 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 half the 50mg tablets to get a dose of 25mg as the dust from breaking a tablet can be inhaled by other people and cause them side effects.

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

One medicine that should not usually be taken with azathioprine is allopurinol, used to prevent gout.

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 azathioprine

A missed dose should be taken twelve hours before the next dose is due. If there is less than twelve hours before your next dose, do not take the missed dose, just take the next dose at the normal time. Never take double doses to make up for missed doses.

Specific information about mycophenolate mofetil

- Mycophenolate mofetil is available as 250mg capsules (blue/brown) and 500mg tablets (purple).

Side effects of mycophenolate mofetil

The most common side effects are:

- **Stomach upset (diarrhea and vomiting)**
- **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

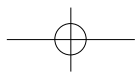
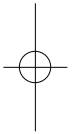
Taking other medicines with mycophenolate mofetil

Do not take iron supplements or antacids (e.g. Maalox®) within 2 hours of taking mycophenolate mofetil

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 mofetil***

A missed dose should be taken at least six hours before the next dose is due. If there is less than six hours before your next dose, do not take the missed dose, just take the next dose at the normal time. Never take double doses 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 reduces 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. After taking prednisolone for more than three weeks your body will stop producing its own steroid and so it is important that you reduce the dose slowly as advised by your doctor.
- 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 them with food may reduce the chance of indigestion.

Side effects of prednisolone

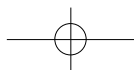
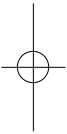
Prednisolone has a number of possible side effects. Most of the side effects happen slowly over a period of time. The doctors will reduce your dose to the smallest amount to prevent rejection. Most people will not take prednisolone after the first three months of their transplant.

- **Stomach upset and indigestion**
- **Swollen ankles**
- **Weight gain due to increased appetite**
- **Rounded face**
- **Diabetes (increased sugar in blood)**
- **Thinning of bones (osteoporosis). You may be started on calcium tablets to reduce this effect.**

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 a dose of prednisolone

If you forget to take your prednisolone but remember before around 8pm, take it and 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.



Sirolimus

- This is a relatively new immunosuppressant. It is only licensed in kidney transplant which means that the government has not authorized it to be used in liver transplant. There are trials underway in liver transplant. It is mainly used when patients develop kidney problems on ciclosporin or tacrolimus.
- The usual starting dose of sirolimus is 2mg once a day. Take it at the same time each day, at the same time with respect to food e.g. always before or always after food.
- The dose is altered according to blood levels. Do not take sirolimus on the morning before your outpatient appointment until after you have had your blood test.

Interactions

Some medicines can increase or decrease your sirolimus level in the blood. This may increase your chance of side effects or rejection. Always check with your doctor or pharmacist if you are prescribed or buy any new medicines. There are various medicines that you should not take whilst on sirolimus, these include two antibiotics called erythromycin and clarithromycin.

If you are also taking ciclosporin (Neoral®) as well as sirolimus it is important that you do not take the sirolimus and ciclosporin at the same time of day. Take the sirolimus one hour before or at least 4 hours after your ciclosporin dose.

You should not eat grapefruit or drink grapefruit juice whilst you are taking sirolimus because it contains a chemical that affects the level of sirolimus in your blood. Other citrus fruits are safe to eat or drink.

Side effects with sirolimus

Sirolimus has several side effects but not everyone will experience them.

Listed below are the most common side effects:

- **Stomach upset including diarrhoea**
- **Increased cholesterol**
- **Acne**
- **Increased risk of infection**
- **Ankle swelling**
- **Anaemia**
- **Reduced wound healing**

You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution. Your cholesterol will be checked in outpatient clinic so changes can be made if needed.

Other Types of medicine needed after a liver transplant

1. Anti-ulcer Medicines

After a big operation, such as a liver transplant, you may be more prone to getting a stomach ulcer. Also, some of the immunosuppressants e.g. prednisolone and azathioprine, can cause indigestion and other stomach side effects. 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.

This is usually ranitidine which is taken as one tablet twice a day. Alternatively you may be given omeprazole or lansoprazole which are usually taken once a day. 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 the prednisolone.

The patient information leaflet in the packet will give you more information about these medicines. Alternatively, ask to speak to the pharmacist.

2. Medicines to prevent infections

Immunosuppressants increase your risk of infection. To reduce this risk you will be given medicines for the initial few weeks.

Fluconazole capsules are taken to prevent fungal infections. You will take them for one to two weeks after the transplant and they are then changed to nystatin oral suspension.

Nystatin oral suspension is used to prevent fungal infections in the mouth (thrush). The dose is 1ml rinsed around the mouth four times a day. You will only take this until you are discharged from hospital after your transplant.

Co-trimoxazole (Septrin®) tablets are given to prevent a particular type of pneumonia that people with reduced immune systems are susceptible to. The dose is one tablet daily for 3 months. While you are in hospital you will be given the full supply of tablets to complete the course. You do not need to get any further supplies.

Valganciclovir tablets are given to some patients to prevent a viral infection known as cytomegalovirus (CMV). CMV is a virus which is common in the population and does not usually cause any problems for people whose immune systems are working well. Before your transplant we do a blood test to check if you have been infected with CMV in the past and are a "carrier". We also test the new liver to see if it is a carrier of CMV. If you do not have CMV, but your new liver does have CMV this is known as a 'mismatch'. Mismatch patients are more likely to get CMV disease which can cause problems including liver transplant rejection. For these people who are 'mismatches', we give a 90 day course of valganciclovir to reduce the chance of getting a CMV infection.

The dose depends on your kidney function but is usually two 450mg tablets once a day. Take with or after food with a glass of water.

3. Pain killers

For the first few days after your liver transplant you will probably have strong pain killers into your spine (epidural) or into your vein when you press a button (patient controlled analgesia or PCA). After this time you will be given pain killers in the form of tablets @ usually paracetamol and dihydrocodeine.

You can take a two paracetamol tablets every four to six hours up to a maximum of eight tablets in 24 hours and dihydrocodeine 30mg tablets at a dose of one or two tablets every four to six hours to a maximum of eight in 24 hours.

You can reduce the doses of the pain killers when you are ready. It is usually wise to reduce and stop the dihydrocodeine first before starting to reduce the paracetamol. If you need to take pain killers in the future e.g. for headaches, colds etc, you can take paracetamol or co-codamol (paracetamol and codeine). The maximum dose is two tablets every four to six hours to a maximum of eight tablets in 24 hours.

It is important that you do not take anti-inflammatory tablets eg ibuprofen (Nurofen®) unless advised to by St James's.

4. Blood pressure tablets

Some patients need to take blood pressure tablets as some of the immunosuppressants can cause high blood pressure. Your blood pressure will be checked at each clinic visit and you may be referred to your GP to start blood pressure tablets.

5. Blood sugar medicines

Some patients may have high blood sugar levels after the transplant. This is known as diabetes and may be caused by some of the medicines you are taking. You may be started on insulin injections or tablets to control your blood sugar. If you need these medicines initially it does not necessarily mean that you will be a diabetic for the rest of your life.

Supply of medicines after your liver transplant

You will receive all your new medicines from St James's for the first three months after your transplant.

You will be given a supply when you are discharged from hospital. You will be able to obtain further supplies from the outpatient pharmacy. When you attend each outpatient appointment, check what supplies you have at home and ask the doctor for a prescription if you are getting low. If you are not sure, bring your medicines with you to clinic and the pharmacist will go through them with you.

After about two months after your transplant your medications should be more stable. Make an appointment to see your doctor at home (GP), to request that you start to obtain supplies through your doctor from three months. If you have any concerns regarding the supply of your medicines, please speak to the pharmacist in outpatient clinic.

As with any medicine, you will need to pay a prescription charge per medicine unless you qualify for exemption. If not, it may save you money to purchase a pre-payment certificate or "season ticket". Ask the pharmacist for more information.

How often will I need to come for outpatient visits after my liver transplant?

For the first few weeks after your transplant you will need to be seen every week in outpatient clinic. At your outpatient appointment you will be weighed, have your blood pressure checked, have blood tests and be reviewed by a doctor.

If you are well and your blood tests are stable, the frequency of your appointments will gradually be reduced. As a guide, by the time it is one year after your transplant you may only be reviewed in Leeds every three months.

Although you will be given an appointment time to come to clinic, patients are seen on a first come, first served basis. So long as you attend before 12 noon for a morning clinic you will be seen.

All patients will be followed up at St James's for the rest of their lives.

A pharmacist should usually be available in the clinic in case you have any queries regarding your medicines. Alternatively you can speak to a pharmacist via the liver unit.

What do I do if I am sick or have diarrhoea?

If you are sick more than an hour after you have taken your tablets, you should not retake them as they will have been absorbed into your blood stream.

If you are sick within an hour of taking your tablets (and particularly if you see remains of the tablets 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.

If you are sick or have diarrhoea for more than 24 hours contact the liver unit. Make sure that you drink plenty of fluids so you do not dehydrate.

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.

Can I use alternative medicines after a liver transplant?

Alternative medicines are “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 Kava Kava, St Johns Wort or Echinacea.

Aromatherapy oils can be absorbed through the skin and get into your body so may have any effect on you and your new liver. If you wish to have a massage we recommend that you only have the base oil (usually almond oil) without any added aromatherapy oils.

We do not advise use any alternative medicines as the effects on your medicines and new liver are often not known.

If you are considering starting to take an alternative medicine, please discuss it with a liver transplant pharmacist first.

Is it safe to have vaccinations after a liver transplant?

If you need a vaccination after your liver transplant it is important to check if it is safe for you to have as some vaccines are safe but some are not safe after a transplant.

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 recognize it and fight it straight away.

There are two main types of vaccination:

- **Live**
- **Inactivated or 'dead'**

Live vaccines have the live bugs in the vaccine. While on immunosuppressants, your body's immune system will not respond as well and you may 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 because the bugs used to vaccinate are not alive, and you cannot get the infection from the vaccination.

If you need to receive any vaccinations check they are not live.

● **Live vaccines:**

NOT SAFE TO HAVE AFTER A LIVER TRANSPLANT

● **Inactivated vaccines:**

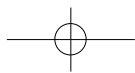
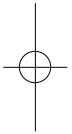
SAFE TO HAVE AFTER A LIVER TRANSPLANT

- Oral polio
- Oral Typhoid
- BCG (Tuberculosis)
- Yellow Fever
- Varicella Zoster (Chicken pox)
- Measles/Mumps/Rubella (MMR) Inactive Polio Vaccine (IPV-injection)
- Typhoid (injection)
- Hepatitis A
- Hepatitis B
- Influenza
- Pneumococcal
- Meningococcal C and A&C
- Diphtheria/Tetanus/Pertussis (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.

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



SECTION 4

Dietary Recommendations

Before your transplant, many of you may have had a poor appetite and had to follow a fairly restricted diet while trying to eat as much energy and protein as you could every day. After a successful transplant much of the dietary advice will no longer be necessary although you will have to follow some advice to ensure you stay as healthy as possible.

Immediately after your transplant

Immediately after your transplant, you will need to eat well in order to ensure you get the correct nutrition to help your wound heal, to build up your body stores and help your transplant work. You may also need to replace any weight that you lost prior to your transplant and while in hospital for your operation. Your Dietitian may have advised you take some nutritional supplements to boost your dietary intake such as Fortisip Protein, Fortijuice, Fortimel, or Calogen. It is important to take these every day for as long as you are advised.

Once you are back to a healthy stable weight, your wound has healed and you feel that you are eating normally again supplements are usually stopped. It is at this point that you should start to follow a healthy diet.

Food hygiene advice following your liver transplant

Some of your immunosuppressive medications lower your resistance to infections. You can contract some infections from food. These are known as food borne infections.

You are most at risk from these types of infections for the first six months following your transplant. Although the risk diminishes after this time it is always higher in people on immunosuppressive drugs rather than those who are not. Therefore it is recommended that you follow the following advice for life. If you do accidentally eat one of these foods don't panic.

Be aware that if you develop food poisoning, nausea, vomiting and diarrhoea contact your GP or the Liver Unit for advice especially if you feel you are not able to take or keep down your immunosuppressive drugs.

The areas to consider involve food selection, food preparation and storage.

You need to be aware of: -

1. Milk

- **Do not drink:** unpasteurised milk (green top) or milk straight from the farm that has not been heat-treated.
- Other types of milk are fine. e.g. Pasteurised, sterilised, UHT, homogenised or powdered. This can be full cream, semi skimmed or skimmed milk.
- If you have milk delivered to your door, do not drink the milk from any bottles that the birds have pecked through.
- Always use milk before it's 'best before' date.

2. Yoghurt

- **Do not eat:** Unpasteurised or live yoghurts. These may also be labelled as 'bio' yoghurts.
- Avoid any probiotic or live drinks and products such as Yakult or Actimel.

3. Eggs

- **Do not eat:** Duck eggs, raw eggs e.g. egg nog, lightly cooked eggs, home made mayonnaise and marzipan. Commercial marzipan is sometimes made with pasturised eggs so check the label.
- Check the labels on commercial mayonnaise. Many use pasteurised eggs in preparation therefore are safe to eat. Salad cream is safe to eat.
- Egg dishes are fine as long as the eggs are cooked completely e.g. scrambled, omelettes, hard-boiled, eggs in cooked dishes. Savoury cooked souffles are fine however sweet souffles with whipped eggs should be avoided.

Avoid runny yolks!

4. Meat & Poultry

- Always ensure that all meat is well cooked.
- **Do not eat:** Purchased ready cooked chickens.
Undercooked meat of any kind.
Reheated meat especially chicken.
Pates made with meat, liver or chicken liver.
- If using frozen meat, make sure that it is properly thawed before cooking.
- You can eat reheated meat you have cooked yourself but only once. Make sure it is piping hot before eating.
- If using a microwave oven, make sure you follow the advised cooking **and** standing times. Make sure the meat is cooked all the way through.
- Keep raw meat at the bottom of the fridge and any cooked food above it. This avoids the risk of raw meat juices dripping on foods that you may be planning to eat raw.
- Keep meat at the right temperature either in the fridge or frozen in the freezer.
- Do not leave meat either cooked or uncooked at room temperature.
- Do not keep cooked meat for more than two days.

5. Fish

- **Do not eat:** Fish roe.
Shellfish purchased loose.
Any raw fish e.g. sushi, oysters.
- Frozen prawns are fine as long as they are defrosted completely before use and eaten immediately.
- All other fresh, frozen or canned fish are suitable if cooked well.
- Shellfish is suitable if pre packed from a supermarket or other reputable outlet.

6. Cheese

- **Do not eat:** French and Swiss soft cheeses e.g. Brie, Camembert, Blue veined cheeses e.g. Stilton. Any cheese with mould on or in it.
- All other cheeses are suitable e.g. Cheddar, Red Leicester, Edam, Philadelphia type cheese, Cheese spreads, cottage cheese.

7. Fruit & Vegetables

- **Do not eat:** Grapefruit or grapefruit containing products. Unwashed fruit and vegetables. Pre packed salads. Salads from delicatessen counters in supermarkets.
- Wash fruit before eating. Peel vegetables if you are eating them raw. If not peelable make sure you cook them until they are piping hot.
- When buying fruit and vegetables, if available choose ones that have some wrapping or packaging round them e.g. a bag of apples, net of onions, mushrooms in a box. Self select fruit and vegetables tend to have been touched by lots of people looking for the nicest ones!

8. Drinks

- **Do not drink:** still bottled water.
- Ice - if having ice make your own. Use covered ice trays or ice bags and store at the top of the freezer.
- All other drinks are suitable including fizzy mineral water.

Always check with the Doctors if you can drink alcoholic drinks.

The Following Points are important when preparing and storing food

- Always use separate chopping boards and knives for preparing raw and cooked foods.
- Use separate boards and knives for preparing meat, fish and fruit and vegetables.
- Store raw and cooked foods separately, with cooked food always above raw foods in the fridge.
- Check dates on goods and always use by the 'use by' date.
- Take chilled or frozen foods home as quickly as possible-do not refreeze food that has already thawed.
- Get fridge or freezer temperature magnets if your fridge /freezer does not do the temperature for you.

Your fridge should be between 0°C and 5°C (32°F and 41°F).

Your freezer should be -18°C.

- Wipe the tops of bottles and cans before opening.
- Add herbs or spices if using them at least five minutes before the end of cooking time.
- Avoid dented cans.
- Discard any decaying food or things you think may be going off.
- Cook food thoroughly.
- Follow the manufacturers instructions when using a microwave oven to defrost or cook food.
- Do not reheat food more than once.
- Wash tea towels at high temperatures regularly.

- Change your dishcloths regularly or use disposable ones.
- Use an anti bacterial surface cleaner in the kitchen. Most supermarkets sell their own brands.
- Always wash your hands with hot soapy water before and after preparing food.
- Keep pets out of the kitchen.
- Wear gloves if gardening and always wash your hands before eating or preparing food.

Suggestions for Eating Out

There is no reason why you should stop going out for meals now that you have had a transplant.

It is important that you choose carefully from the menu and do not choose any of the foods previously listed to avoid. Try to go to restaurants that you feel are clean and reputable. Most restaurants will be more than happy to help you.

- Ask for meat or fish to be well cooked. If any of the flesh is pink ask for additional cooking.
- Do not eat dishes even if cooked, that contain shellfish.
- Ask how sauces or dressings have been prepared and do not eat any that contain raw eggs.
- Avoid high-risk foods from buffets such as eggs, cream dishes, rice, and rare beef. Try to be first at the buffet as you can be more confident the food has not been at room temperature for long or many different people touched what you are eat. Alternatiely ask for a plate to be made up for you straight from the kitchen.
- **Do not eat** cream with desserts.

Indian, Chinese or Italian meals are all fine providing that they are well cooked and do not contain any food listed in the 'do not eat' section. Rice eaten with these meals should be freshly cooked. Chapatti, Nan and other breads are fine.

If you are going abroad and are concerned about the food available, please contact your Dietitian for advice.

If you would like to see a Dietitian about any aspect of your diet please feel free to ask while you are on the ward or when you attend clinic.

Healthy eating

Following your transplant, you should now be able to put on some body weight if you were underweight. It is normal for your post transplant weight to be higher than your pre transplant weight.

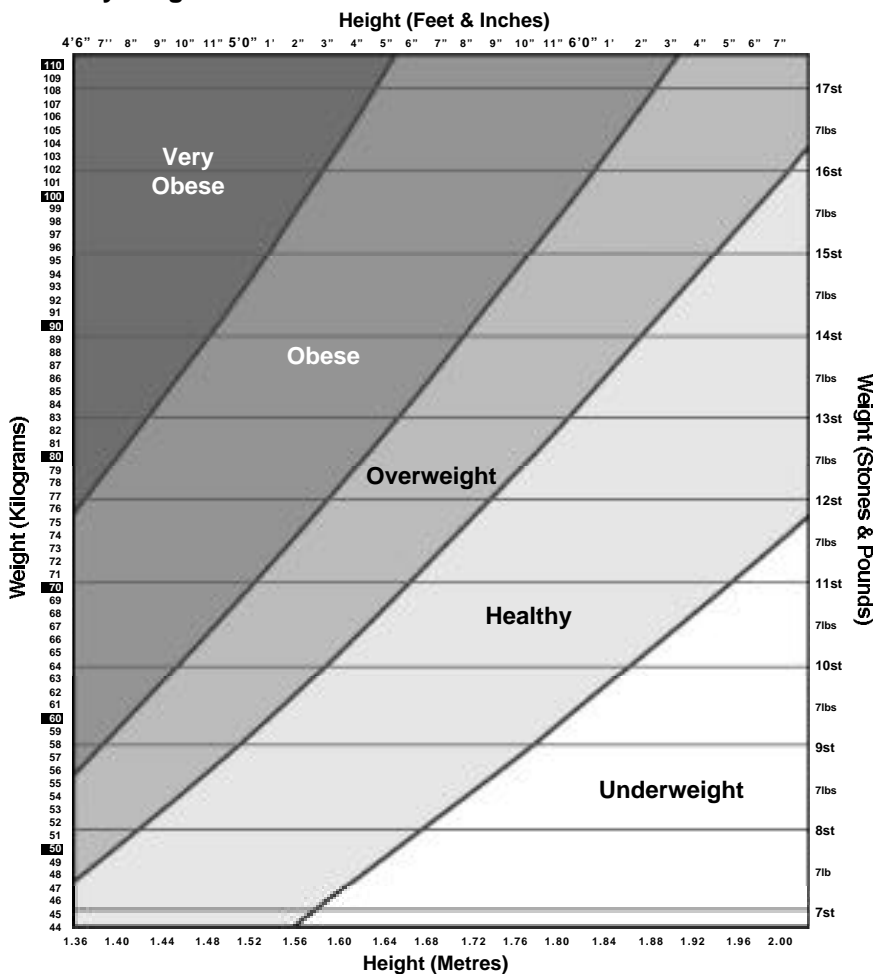
It is important to realise what is a healthy weight is for you. Discuss your weight with your Dietitian and give yourself a target weight. It is important that once you reach your healthy weight you do not put any extra weight on. It is always harder to loose extra weight once it has been put on!






Excess weight can lead to high blood pressure, heart disease and diabetes.

Are you a healthy weight?

Use the chart below to see if you are a healthy weight. Measure your height (without shoes) and your weight without clothes on. Look to see where you are on the chart and if you are a healthy weight.

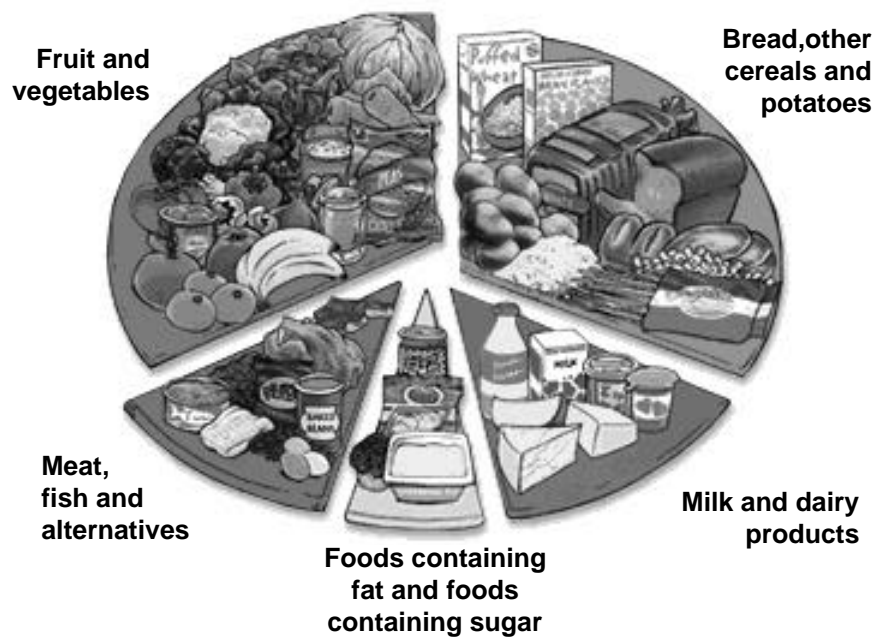
A healthy weight is a BMI = 20 -25



- 
Very Obese
 Health is seriously at risk. Losing weight immediately is essential
- 
Obese
 Health is at risk. Losing weight now should be seriously considered
- 
Overweight
 Health could suffer. Some weight loss should now be considered
- 
Healthy
 A healthy weight
- 
Underweight

Guidelines for a Healthy Diet

- Enjoy your food!
- Eat a variety of different foods
- Aim to keep your weight within a healthy range
- Eat plenty of foods rich in starch and fibre
- Do not eat too many foods that are high in fat
- Don't eat sugary foods too often
- Avoid having salt and salty foods too often



The diagram above is to give you an idea about how much of your diet should be made up from each of the food groups.

Fruit & Vegetables

These provide valuable fibre, vitamins and minerals with little fat.

- Aim to have five portions a day.
- Fresh and frozen vegetables can be equally nutritious.
- Include pulses such as peas, beans, lentils and oats as much as possible.
- Try to eat some at each meal.
- Eat fruit and vegetables as healthy snacks rather than sweets and biscuits.

Meat & Fish and alternatives.

Meat, poultry, all fish, eggs, nuts, beans, chickpeas are all included in this group.

- Eat moderate amounts and choose lower fat versions when you can.
- Grill, poach, bake or microwave rather than frying. Do not add extra fat
- Choose lean cuts of meat, lower fat versions and trim off any visible fat.
- Remove skin from poultry.
- Include more fish, chicken and turkey in your meals.
- Aim to have oily fish 2-3 times a week. These fish are mackerel, sardines, herrings, pilchards, salmon, fresh tuna, sprats, snapper, shellfish (remember food safety guidelines!) and anchovies.

Bread, Other Cereals and Potatoes

'Other cereals' means things like breakfast cereals, pasta, rice, oats, noodles, maize and millet.

- Try to eat wholemeal, wholegrain, brown or high fibre versions of all of the above where possible.
- Use these foods to make you feel full.
- Try to avoid adding too much fat. For example thinly spread butter, margarine, low fat spread on bread, or rich sauces such as cheese or cream to pasta.

Milk & Dairy Foods

This group includes milk, yoghurts and cheese. They are a valuable source of calcium

- Eat and drink moderate amounts and choose lower fat versions where you can.
- Try using skimmed or semi skimmed milk instead of full cream milk.
- Try using lower fat versions of yoghurts, but not bio.
- Choose lower fat cheeses such as Edam, Emmental, Cottage cheese, and reduced fat Cheddar.

Fatty & Sugary Foods

Included in this group are margarine's, butter, low fat spread, oils, salad dressings, mayonnaise, cream, Chocolate, crisps, biscuits, pastries, cakes, puddings, ice cream, rich sauces, sweets and sugar.

- Use low fat spread (e.g. Flora light, Delight, Gold, Olivio light, supermarkets own brands), spreads made from olive oil (e.g. Olivio, golden olive, supermarkets own brands), instead of butter and ordinary margarine.

- Whatever spread you use, use it sparingly.
- Some foods contain hidden fat and should be eaten only occasionally. These include pies & pastry dishes, cakes and biscuits.
- Use low fat salad dressings and reduced fat pasteurised mayonnaise.
- If you cook in oil try to do so infrequently. Try to choose monounsaturated (e.g. rapeseed, olive) or polyunsaturated oils (e.g. sunflower) and use small amounts.
- Use low calorie squashes, water or diet pops if having soft drinks.
- Use artificial sweeteners in drinks, breakfast cereals and puddings rather than sugar.
- Cut down on sweets, chocolates and crisps. Aim to have only occasionally.

Salt

You may have been told to restrict the amount of salt in your diet before your liver transplant to stop fluid building up. Following a transplant your new liver will be able to handle salt better. However a high salt intake is not good for anyone. Also following a transplant you are more prone to developing high blood pressure and diabetes than people without a transplant. A reduced salt intake helps with both these conditions.

- Do not add salt to your food at the table.
- Use only small amounts of salt in cooking.
- Limit salty foods such as crisps, nuts, bacon, canned soups, tinned foods, packet or bottled sauces, chutney, convenience meals.
- Avoid salt substitutes such as Lo Salt, Sea Salt.
- You can use herbs, garlic, spices, pepper, mustard and vinegar to flavour food.

Alcohol

If you have been advised not to drink alcohol it is important that you continue to follow this advice.

If your Doctor says you can drink alcohol it is important to drink within safe limits.

For general health the recommended safe limits are shown below.

- **Men: maximum of 28 units a week**
- **Women: maximum of 21 units per week**
- **1unit= 1/2 pint of beer or lager (standard strength) or 1 small (125ml) glass of wine or 1 pub measure of spirits.**
- **Try not to have more than 2-3 units a day.**
- **Have a few alcohol free days every week. Do not save all units up for one day!**

Low Potassium diet

Not everyone who has a transplant needs to follow a low potassium diet.

Your Doctor or Dietitian will advise you if you need to follow this diet.

Potassium is a substance in your blood, which is normally passed out in your urine if you have more than you need in your blood stream. Some of your immunosuppressive drugs can make you hold on to too much potassium. A high level of potassium can be dangerous as it can effect your heart.

If a high potassium level is detected in your blood you may be asked to avoid foods that contain a lot of potassium in them. Your potassium will be checked regularly and you will be advised when you can stop the low potassium diet.

Foods to avoid that are high in potassium

Suitable alternatives

Potatoes

Chips, oven chips, frozen chips, microwave chips, instant mash, jacket potatoes, potato waffles, potato croquettes.

Boiled or mashed potato-
Up to 3 small potatoes a day.
Boiled rice, pasta
(any type or shape),
cous cous. Any bread.

Vegetables

Baked beans, butter beans, chickpeas, red kidney beans, haricot beans, mung beans, lentils, spinach, mushrooms, tinned tomatoes, tomato puree, brussel sprouts, parsnips.

Carrots French/green beans, broccoli, cabbage, leeks, cauliflower, swede, turnips, sweetcorn, onions, peas, mange tout, beansprouts, celery, mixed vegetables.
Small tomato a day,
lettuce, cucumber.

Fruit

Apricots, banana, damsons, rhubarb, cantaloupe melon, dried fruit e.g. raisins, sultanas, prunes, dates, figs, blackberries, red currants, blackcurrants, grapes, avocado, cherries.

Apples, pears, peaches, small oranges, pineapple, raspberries, strawberries, lemon, mandarin, plum, kiwi fruit, small nectarine, tangerine, satsuma, tinned fruit in syrup.

Drinks

Coffee, cocoa, fruit juice, blackcurrant squash, horlicks, ovaltine, bournvita.

Tea, other squashes, lucozade, lemonade, tonic water, fizzy pops, diet pops, water.

Snacks

Potato crisps, nuts, marzipan, liquorice, fudge, and marzipan. Cakes and biscuits containing chocolate, coconut, coffee or dried fruit.

Maize or corn snacks e.g. monster munch, wotsits, tortilla chips, boiled sweets, mints, butterscotch, marshmallows, jelly babies, barley sugar, fruit pastilles, chewing gum.

Cereals

All Bran, museli, Bran Buds, Farmhouse bran, fruit and fibre, sultana bran, Nutrigrain, Ready brek, oatcakes, rye crisp breads.

Cornflakes, rice krispies, weetabix, shredded wheat, riccicles, honey nut loops, crunchy nut cornflakes, shreddies, start, special K, weetaflakes, bran flakes.

Miscellaneous

Spaghetti in tomato sauce, tomato sauce (stick to 1 tablespoon only) Curry powder.

Plain and cream cakes, jam roll, doughnuts, sugar, honey, jam, plain biscuits, jelly.

- You can reduce the amount of potassium in vegetables by boiling them.
- Boil them in lots of water and discard the cooking water. Do not use it for soups, gravy or stocks.
- **Do not use** a pressure cooker, steamer or microwave for cooking vegetables and potatoes.
- Once you have boiled your potatoes you can make them into chips or roast them.
- Only have two small serving of vegetables a day.
- Only have two pieces of fruit a day.
- Limit potatoes to 3 small ones a day.
- Fill up on breads, rice, pasta, meat, fish, and cheese and dairy products.

SECTION 5

General Health

Alcohol

Before taking alcohol again please make sure you get advice from the clinic. If you had your liver transplant due to alcohol this issue will already have been addressed.

Dental Care

After your transplant, you should continue your regular 6 monthly dental check-ups. 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. Please let your doctor know if you have a sore mouth, this may be due to an infection.

Driving

This is up to the individual, perhaps between 3-6 months after you have been discharged from hospital, but please don't forget how tired you may become. If you must drive, it is best to have someone with you. You must inform DVLA in Swansea and you should advise your insurance company.

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 and show toe, foot and ankle exercises to help with circulation and muscle strength until you start mobilising 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 the effect of some 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 & 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 doing, let your body recover from the surgery first.

Walking

- Walking is one of the best forms of exercise!
- Build up slowly, half a mile at a time, every two to three days. The distance you achieve will depend on your age and severity of your health pre-operatively.

Always remember, if you have CHEST PAIN, LEG PAIN or SHORTNESS OF BREATH, DIZZINESS OR LIGHT HEADEDNESS STOP & REST!

You have probably done too much too soon.

Yoga and Pilate's 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 previous to your transplant.

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 any details.

Returning to Work

This depends on your job and on your general health as an individual. Lifting must be avoided for the first three months and then good lifting technique must be maintained at all times. It is best to discuss going back to work with the transplant doctor as it may be as soon as three months after your transplant.

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 progress, you may find it takes time for your sex drive to return and this is quite normal. Don't forget contraception as some contraceptives are not advised after a transplant, discuss this with your doctor.

The transplant physiotherapist can be contacted on bleep 5636 via the hospital switchboard, or directly on the liver unit (ward 71). The physiotherapist may also be able to give advice or exercise programmes at clinic appointments if required.

Holidays Abroad

Good idea! Don't stop them, although please check with the transplant doctors to see if you are fit to travel. It is usually sensible to wait a year after your transplant before travelling abroad.

- Please make sure you have enough medicines, as you will probably be unable to obtain certain types in some countries.
- Travel insurance is strongly recommended.
- Take care with drinking water. Do not drink ice even on the plane, as the water is recirculated.
- It is safer to visit countries where there are adequate medical and sanitary facilities.
- You must **never have any** vaccinations without first consulting your transplant pharmacist. Some vaccines contain live viruses which could be life threatening.
- If you are going to an area where malaria is present it is **essential** to contact the pharmacist at the outpatient clinic four weeks before going away, as advice regarding ant malarial prophylaxis differs from country to country.

Infections

Because of your physical condition and the medicines you need to take, you are prone to infection.

If you get any of the following please contact your GP or the hepatology liaison sister.

- Rising temperature (normal temperature 37C/98.6F). A high temperature is considered to be over 37.5C
- Pain, burning, difficulty passing urine.

- Sore throat, cough or cold.
- Inflamed, red or painful wound site
- Cold sores.
- Headaches and sensitivity to bright lights.

Remember **hygiene** is very important. It is essential to maintain a high standard at all times.

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 hepatology sister who may advise you to have a blood test at your GP.

Women's Health

We advise you to have a cervical smear once a year, along with a breast examination, as there is a small increase in the risk of developing cancers when taking immunosuppressive medicines. At home 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 pharmacists on the unit.

Initially after your transplant you may find that your tummy is tender, therefore when having sexual intercourse try to find the most comfortable position. Should you be contemplating pregnancy we advise careful counselling prior to conception so as to reduce the risk to you and your baby. We suggest you wait 1-2 years post transplant.

Home delivery is not suitable.

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

Pets

Keep away from caged birds as they can cause lung disease in patients on immunosuppressive medicines. Cats and dogs are safe if they 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. Smoking inevitably reverses the benefits of a successful transplant.

Sunbathing & Skin cancer

Immunosuppressants do speed up tanning so you will tan faster and suffer from sunburn if precautions are not taken. It is known that patients who are on immunosuppressants are more prone to skin cancer. It is therefore important that you follow these instructions;

Do not sunbathe between the hours of 11 noon and 3pm

Sit more in the shade than in the sun

Wear a high factor sunscreen-factor 15 or higher

It is important to apply this sunscreen on all exposed skin even on mildly sunny days between April and late September

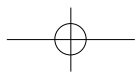
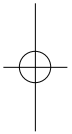
It is also important to apply sunblock 2-3 times a day when the sun is very intense-even in England

Tattoos & Piercing

Please do not have any tattoos or piercing done in an unreputable establishment as they can transmit blood borne viruses and infections.

Work

This depends very much on your job and on your general health as an individual. **Lifting must be avoided** in the first 3 months and then a good lifting technique should be maintained after this. Discuss going back to work with the transplant doctor.



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 pre-transplant assessment. She is available to help throughout the process of being on the waiting list, having the operation and as you recover afterwards.

It helps us as a team to help you if we are more aware of your individual situation rather than just your medical condition. The social worker will therefore explore with you any issues such as employment housing, finance, benefits, social and family support etc. which may be causing you problems.

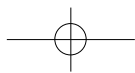
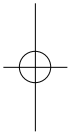
Remember the social worker is there to help you and your family if you are having problems, or if you feel you would benefit from a 'listening ear.'

Travelling costs

The Liver Unit may be a distance from your home town. For some patients and their families this can cause difficulties practically and financially. 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.

The Liver Unit has a flat in a tower block, opposite the hospital entrance, where we can accommodate relatives who wish to be near at hand. The flat has 2 bedrooms (each with 2 single beds) and shared lounge, kitchen and bathroom facilities.

Beds are allocated on a priority basis, therefore the availability of the flat cannot be guaranteed in advance. Please ask the nurse in charge on the liver unit for further information.



SECTION 7

Letter of Thanks & Support Group

Letter of thanks

Some transplant recipients feel they want to write and thank the family of their donor for enabling them to be transplanted. It is possible to know something about the person who donated their liver to you and also the family who so kindly and unselfishly thought of others at a time of great sadness. This information is anonymous, to maintain patient confidentiality. Likewise if a family of the donor asked for information about you they will be informed of the age, sex, and geographical location of the organ recipients. Furthermore they are thanked on your behalf for this gift of life.

If you wish to write a letter to the donor family, following your liver transplant it is possible to do this. We encourage you to write a letter as the majority of families love to hear from transplant recipients. Following the death of a loved one organ donation is the positive outcome from a tragic situation. The transplant co-ordinator can access information regarding your donor and help and support you when writing a letter.

The transplant co-ordinators can be contacted at St James

Tel: (0113) 2064930

or alternatively contact the hepatology liaison nurses on

Tel: (0113) 2066585.

The Transplant Support Group

The Support Group was set up some years ago, to provide ongoing support to transplant patients and their families and an opportunity for people to meet. We also give support and information to pre-transplant patients and their families.

We currently meet every three months in the hospital. Some of our members have raised money, which has been used to buy items for the ward.

We aim to support Transplant Awareness Week and there are also planned social events. You can still join the support group even if you cannot attend the meetings. Just send your name and address to

Janet Atherton
4 Tennyson Avenue
Leigh
Lancashire
WN7 5LG

Tel: 01942 704385

Email: ajantath@aol.