

Liver Transplant

Going Home

Your questions answered

PIL Liver Transplant Going Home v5 Layout & Readability reviewed by NHSL Patient & Carer Information Team
Authorised: Jan 2020 , for annual review, this version authorised for print to Jan 2025



Going home

your questions answered

Going home
“Your Questions Answered”
Fifth Edition May 2019
Published by the Scottish Liver Transplant Unit



Contents

Section 1 - Follow-up care

Follow-up clinic	5
Travelling expenses	7

Section 2 - In the Beginning....

Medications	8
Nutrition	10
Improving your fitness	14

Section 3 - Help

Organ donation & transplantation	18
Social, financial and personal support	19
Spiritual & religious support	21

Section 4 - General Health

Risk of infection	22
Skin protection	24
Screening programmes for cervical, breast & testicular cancer	25
Osteoporosis	26
Alcohol	27
Stopping smoking	28

Section 5 - Real Life

Back to work	29
Driving	30
Going on holiday	31
Sexual relationships	34
Contact Information	36

Appendix

Food Safety Post Transplant	38
-----------------------------	----

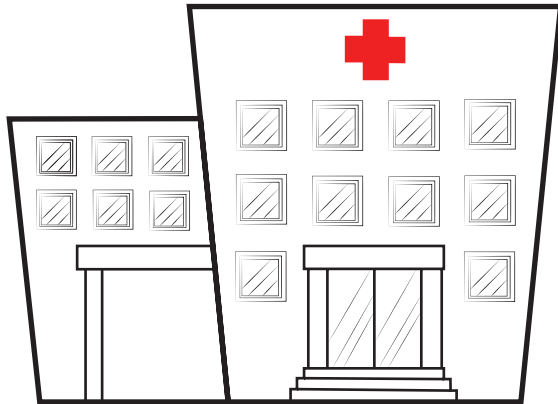
Introduction

Recovering from a liver transplant is a unique experience and your need for advice and support from the Transplant Unit will vary in the months and years ahead.

We hope that the following information will help you to gain the confidence and knowledge you need to return safely to your normal everyday life.

The booklet offers general advice for all liver transplant recipients and suggests ways in which the various members of staff at the Transplant Unit may be able to help you with specific queries or problems.

Please remember that you can contact the Transplant Unit at any time for help and advice or if you become unwell in any way.



Follow-up care

Clinic Follow-up

You will have to attend follow-up clinics for the rest of your life but visits will become fewer and further apart as you get better.

Why do I have to attend clinic?

The purpose of attending clinic is to monitor the function of your new liver and detect any problems as soon as possible. Clinic visits are an opportunity for you to ask any questions that you or your family may have.

What will happen at clinic?

The doctor or the transplant co coordinator will:

- discuss your current health
- check your weight & blood pressure
- examine your wound
- may do a physical examination
- take blood tests to check your liver function, kidney function and blood count
- take a blood test to check your blood tacrolimus / cyclosporin level
- check for any signs of side effects from your medication
- check for any signs of rejection or infection.

Always omit your morning dose of Tacrolimus (Adoport/Prograf/ Advagraf) Ciclosporin/Sirolimus before coming to clinic. Bring it with you to take after you have had your blood drawn.

Re-admission to the Transplant Unit

In the early days/weeks post-transplant it is not unheard of for patients to be readmitted to the unit. This would typically be if you are unwell or if something abnormal is picked up in blood tests at clinic. Admission allows us to arrange further investigations and treatment.

How often will I attend clinic?

The following table is a guide but your follow-up visits will depend on your rate of recovery and the distance you have to travel to the Transplant Unit.

Time after transplant	How often	Where	Day
Discharge-6 weeks	1 - 2 weekly	Royal Infirmary	Tuesday - am
6 weeks-3 months	2 weekly	Royal Infirmary	
3 months-6 months	4 - 6 weekly	Royal Infirmary	Or
6 months-1 year	Every 2 months	Royal and local hospital	
after 1 year	3 - 6 monthly	alternate visits between Royal, and local hospital	Thursday - am

The Transplant team do Outreach Clinics in several referring hospitals. It may be suitable for you to attend one of these instead of travelling to Edinburgh. Telephone Clinics are also offered to patients who are well and have stable blood tests.

Who will I see at clinic?

Tuesday	Thursday	Always available
Transplant Consultant	Transplant Consultant	Dietitian
Transplant Surgeon	Transplant Registrar	Physiotherapist
Transplant Co-ordinator	Transplant Co-ordinator	Social Worker
		Pharmacist

The transplant co-ordinators are usually present at your Medical Out-patient Clinic visits at the Royal Infirmary and will be closely involved in your follow-up care. They may need to contact you at home if there are changes to your medication or if you need to be readmitted to the transplant unit. They also help to ensure the smooth running of any shared care between your local hospital, your GP and the transplant unit.

Travelling to the Royal Infirmary

Travelling to the Royal Infirmary after your discharge from hospital can be time consuming and expensive. Family members and friends should be involved with helping you get to your appointments. Patient arranged hospital transport may be available although this is a limited service. Contact number is 0300 123 1236.

Reimbursement of travel expenses

You may be able to get some financial help to cover your travel costs. Any concerns regarding this should be discussed with the Transplant social worker. The clinic nurse should be able to give you a Certificate of Attendance.

In the Beginning

Medications



What tablets do I take when I go home?

In preparation for going home you need to learn all about your medicines. The Transplant Unit pharmacist will give you information leaflets explaining each medicine and a medication reminder booklet with the exact details of the medicines you are taking. The booklet provides you with an updated record of your medications and it is important that you bring it with you to every clinic visit.

Your medication is reviewed at each clinic visit

- The doses of your immunosuppressants may be changed but you have to take them every day for the rest of your life
- Your antibiotic, antifungal and antacid medicines are usually stopped after 3 months
- You may be started on new medicines to treat any new problems or side-effects that occur.

How do I get further supplies of medicine?

You will leave hospital with a seven day supply of your medicines and a letter for your General Practitioner which lists these medicines. Please hand this letter into the GP practice as soon as possible after leaving hospital so he can renew your prescription before your seven day supply runs out.

Is it safe to take other medicines?

Other medicines may interfere with your Tacrolimus (Adoport/Prograf/Advagraf) Ciclosporin/Sirolimus. Make sure that any doctor prescribing you new medicines is aware that you are on immunosuppressants. If you are buying any medicines over-the-counter check with the pharmacist that they are safe for you to take.

If in doubt, contact the Transplant Unit for advice.

What about herbal and homeopathic remedies?

Herbal and homeopathic remedies contain active ingredients which may interfere with your Tacrolimus (Adoport/Prograf/Advagraf) Ciclosporin/ Sirolimus or the function of the liver - always check with the Transplant Unit before taking any alternative medicines.

What should I do if I forget to take my medicine?

If you remember within 2 hours, take it then. Otherwise hold off until your next prescribed dose. **NEVER TAKE DOUBLE THE DOSE.**

What should I do if I am vomiting or have diarrhoea?

If you are vomiting or have diarrhoea then your medicines may not be absorbed properly. If your vomiting or diarrhoea persists for 24 hours, contact your GP.

**If you have any questions about your medicines please contact the Transplant Unit.
The number is inside your green booklet.**

Nutrition

After a successful liver Transplant your appetite and dietary intake should gradually return to normal.

However your liver disease may have left you undernourished and it may take you a bit longer to get your appetite back. You may well need to take supplement drinks after your transplant and the dietitian will advise you on this and arrange for these to be prescribed by your GP for home.



Should I avoid Salt?

It is advisable to continue on a no added salt diet for the first three months after your transplant. You will be on steroids (Prednisolone) at this time which encourage fluid retention and an excess salt intake may further increase this. Excess salt intake is linked with high blood pressure which can be a problem after transplant.

Salt substitutes are not recommended as they contain high levels of potassium.

Will I gain weight?

Now that you are feeling better and not on any dietary restrictions you are likely to be eating more than you were before your transplant. You are taking steroids and other immunosuppressant drugs which can cause an increase in fluid retention and an increase in appetite. As a result you may gain weight. In some patients this can be excessive and a healthy calorie- controlled diet is very important.

What can I do to prevent excess weight gain?

Once your appetite and dietary intake is back to normal it is important that you maintain your weight within a healthy range and the dietitian can give you guidance on this. Following a healthy diet at this stage and increasing your activity level by doing some gentle exercise is important in preventing excess weight gain. If you are concerned about weight gain please ask to speak to the dietitian at your next clinic visit.

What is healthy eating about?

- Is about enjoying a variety of foods and understanding how the food we eat affects our health
- Is about cutting down on fat, sugar and salt and eating more fruit and vegetables
- It is about making gradual changes to what you eat and changes to your eating habits that become part of your lifestyle
- It is about eating the right amount to be a healthy weight for your height
- It is about having the occasional treat- but not too many!

Healthy eating means eating a balance of foods from the following groups:

Starchy foods - Eat a variety of bread; potatoes, cereal pasta and rice including wholegrain varieties (avoid lots of butter and fattening sauces!).

Fruit & vegetables - Try and eat five portions of fruit and vegetables per day. This may sound a lot but could include a glass of fruit juice, a banana, a portion of salad in your sandwich and a portion of vegetables with your evening meal. **DO NOT EAT GRAPEFRUIT OR DRINK GRAPEFRUIT JUICE.**

Milk and dairy produce - choose lower fat types e.g., semi- skimmed milk, low fat cheese and low fat yoghurts etc.

Fats - Use low fat alternatives to butter and margarine where possible and avoid using fat to cook e.g. use spray oils or dry fry.

Sugar/ sugary foods & drinks - Limit your intake of sugary foods to an occasional treat- choose diet/low sugar varieties where possible.

You cannot eat grapefruit as it interferes with the absorption of your immunosuppression medication.

Food Safety

Following a liver transplant it is recommended that you avoid high risk foods for up to 6 months and follow good food safety rules within the home.

Please see food safety information in the appendix section at the back of this booklet.

How can I contact the dietitian?

If you have any concerns about your diet please contact the dietitian either on your next clinic visit or by telephone on **0131 242 1252.**

Fitness

Before your transplant you may have felt too tired or too unwell to exercise regularly. The less you do, the weaker your muscles get. Now you have had your transplant you should aim to regain your muscle strength and general fitness. This can be achieved by regular exercise.

How do I start?

During your stay in hospital you will be given an exercise programme by your physiotherapist - practice this daily and continue at home.

START EXERCISING SLOWLY AND PROGRESS GRADUALLY

What types of exercise will I have to do?

Different types of exercise will help in different ways

Flexibility - gentle muscle stretching will stop you getting stiff.

Aerobic - these exercises make your heart and lungs work more and increase your stamina.

Strengthening - these exercises will make your muscles stronger.

An exercise programme involves three stages...

Warm up - light exercise and stretching increase the blood flow to the muscles, getting them ready to work harder - this must always be done at the start of your programme.

Exercise - you should exercise enough to make you out of breath, slightly tired but NOT exhausted.

Cool down - slow the pace down and finish with stretching to let your breathing return to normal.

Also consider the following:

- Avoid strenuous abdominal exercise to help prevent any incisional hernia i.e. sit ups or lifting weights
- your muscles may feel tired but they should NOT be painful - as you become fitter you will need to exercise more to make further progress
- listening to music may make exercise more fun
- choose a time convenient for YOU
- if you feel very tired and take a long time to recover you are doing TOO MUCH.

How do I measure my progress?

Keep a diary- write down the number of exercises you do and the time they take

Measure distance- choose a distance you can comfortably walk and time how long it takes you. As this becomes easier gradually increase in distance.

Are there times when I should NOT exercise?

Yes..... Do not exercise:

- directly after a meal
- if you have a temperature
- if you have a cold or the flu
- if you feel generally unwell.

When you return to your exercise programme start at an easy level and progress. If you experience sudden pain or shortness of breath while exercising -**STOP**. Contact your GP if it persists.

When can I return to sport?

You will be able to return eventually to most sports other than direct contact sports which could cause injury or internal damage. Gentle sports such as swimming and walking are excellent ways to regain your fitness. From an infection point of view, it is safe to go swimming after about three months.

If you enjoy sport, why not support your local Transplant Team at the Transplant Games?

Remember, your fitness has been impaired over a period of time, but by setting goals and progressing gradually you will see steady improvement.

Why might I have a sore back?

You may have a backache for a variety of reasons:

- weakness of your stomach muscles due to your surgical wound
- poor posture
- prolonged bed rest
- osteoporosis (thinning of the bones).

How can I help ease the pain?

- Take care when bending eg. getting into and out of the car or making your bed
- Practice the abdominal muscle exercises you were taught in hospital. These muscles help support your spine
- Do not slouch when you are sitting. Use a cushion or a rolled up towel in the small of your back. Use this every time you sit down - Even in your car!

Walk TALL. Try not to stoop. Stooping and slouching strain the ligaments attached to your spine.

When you bend, remember to use your knees, not just your back. You will be shown how to 'bend' before you are discharged from hospital.

Remember STRAIN causes PAIN!

If you have constant or acute backache please contact your GP.

Help!

Organ donation & transplantation

Your life changing liver transplant was only possible thanks to the generosity of your donor and their family's courage and support for donation. The gift of organ donation is the start of a physical and emotional journey for you as a recipient and for you and your family and friends as you recover and look forward to a better life.

Your donor's family are coming to terms with life without their loved one and many take great comfort from the knowledge that their last act was to save lives through the gift of organ donation. Donor families get a great comfort from receiving a letter from their loved one's recipient and knowing that their gift is truly appreciated.

The transplant co-ordinators can provide you with limited details about the donor but for reasons of confidentiality both you and the donor will remain anonymous.

What can I say and not say on social media?

We live in an increasingly digital age and you may want to share news of your transplant across social media. Please remember that your good news is your donor families' bereavement and we don't want the privacy of either of you to be compromised. Therefore please do not share the date and hospital of your transplant and treat any information you have about your donor family in strictest confidence.

Social, financial & personal support



Transplant Unit Social Workers are available to work with you following transplant and during recovery to assist with issues that may impact both on your recovery and quality of life.

The service may be accessed by you, your family and carers where applicable. It may include support, advice, information, access to counselling and referrals to other services where appropriate.

What practical help is available?

There are a range of Community Care services offered by local Councils which may be useful, or even essential, to you at home. The social worker can work with your local Social Work Centre to set these up and monitor them. The times when this may be needed are:

- Planning hospital discharge/package of care/Carers or young carers
- Recovery
- Any change of circumstances.

This is particularly important for parents with dependent children, patients whose partner is unwell or disabled, people who live alone or in an isolated area.

Can I get help with my finances?

Finances are affected when your circumstances change. You or your family may have questions and require advice about the following, for example:

- Welfare Benefits
- Travel costs
- Employment / Voluntary work
- Education / Training.

The social worker can discuss the implications of any change in your financial circumstances with you or your family and ensure that you are receiving the financial help to which you are entitled.

Can I go back to work?

Returning to work may raise many different questions for you and your relatives, your employer and your colleagues. Most people are able to plan going back to work at three months following transplant. The transplant team can provide information and advice regarding this at clinic or by phone. Social workers can support with confidence building prior to work and can contact employer on patient behalf.

What can I do if I am having difficulty coping?

There may be times when you need to discuss more personal aspects of your experience of illness and recovery.

The social worker will see patients/carers daily on the ward. After discharge she can arrange to see you in the outpatient clinic or can refer you to a local agency for support.

How can I contact the social workers?

The social workers can be contacted on 0131 242 7850, Monday - Friday, 9.00am - 5.00pm. They can be available outwith these hours by arrangement.

Spiritual and religious support

If I wish continuing spiritual and religious care when I am at home, is there anyone who can help?

Most communities are served by a number of religious leaders and spiritual advisers of different churches and faith groups.

How can I contact them?

The hospital chaplains will be pleased to give us their names and addresses or contact the one of your choice at your request. Referrals of this kind will be made only with your expressed agreement.

Is it possible to continue to see one of the hospital chaplains who has been visiting me while in hospital?

Yes. Continuing contact can be arranged. Meetings will normally take place when you attend for clinic visits or at some other mutually convenient time.

How can I contact the Hospital Chaplain?

The hospital Sanctuary is open for all to visit on the ground floor. Referral to the Chaplain can be made at your request. The Pastoral Care office within the Sanctuary can be reached on 0131 242 1990 9am-5pm.

General Health

Your risk of infection following a Liver Transplant

Your immunosuppressant medicines reduce your body's ability to fight infection. The risk of becoming unwell with an infection is greatest in the early weeks and months after your transplant.

What can I do to avoid infection?

- avoid close contact with adults or children who are ill with an infectious disease eg. the common cold, chicken pox, flu, glandular fever
- you should get the flu vaccination each winter from your GP
- you should get the once only pneumococcal vaccination
- always wash your hands after going to the toilet
- always wash your hands after changing a baby's nappy or handling any human or animal waste
- keep any open cuts or sores clean and covered with a dry dressing.

Are there some infections that I cannot avoid?

Yes - some infections are caused by viruses that you have been exposed to before your transplant. These viruses can become active again and cause infection which may require treatment. Examples of these sort of viruses are:

- the herpes virus which causes cold sores
- Cytomegalovirus (CMV) which can cause fever, ill health or infection of specific organs including your new liver.

How will I know if I have an infection?

Most infections will make you feel generally unwell with any of the following:

- raised temperature
- sweating
- shivering / feeling hot and cold
- tiredness
- nausea with or without vomiting
- diarrhoea.

What should I do if I come into contact with someone who is ill with an infectious disease?

Social contact with most routine infections is not a cause for concern and generally requires no treatment. If you are in close contact with a person who has shingles or chicken pox you should contact the transplant unit.

If you are in doubt or worried, contact the transplant unit. There are some infections which may not make you feel unwell immediately but which can be detected in your blood at a routine clinic visit and may require treatment.

Always contact your GP without delay if you think you have an infection. Early treatment is very important!

Is it safe to take antibiotics for an infection?

Most antibiotics are safe for you to take and it is always preferable to treat any infection that is detected. However, there are some common antibiotics that can interfere with your Tacrolimus (Adoport/Prograf/Advagraf) Ciclosporin/Sirolimus which you should not take. Two examples of antibiotics that can interfere in this way are Clarithromycin and Erythromycin.

Always check with your GP that the antibiotics you have been prescribed are safe to take with Tacrolimus (Adoport/Prograf/Advagraf/Ciclosporin/Sirolimus) before you start the course.

Prevention and Screening

Transplant patients should not have any preventive vaccinations that are LIVE vaccines. THIS INCLUDES THE SHINGLES VACCINATION. (Please see section on foreign travel vaccinations).

Your immunosuppressant medicines reduce your body's ability to detect and destroy abnormal cells which may increase your risk of developing certain types of cancer. It is important to follow general health advice which may help prevent a developing cancer or ensure the early detection of malignant changes.



Skin protection

Carefully read the information about skin cancer for patients with an organ transplant from the British Association of Dermatology that is issued at discharge.

Exposure to the sun can damage your skin and increase your risk of developing skin cancer. Because of your anti-rejection medication your body is less able to protect itself against the damaging effects of the sun on your skin. You MUST take sensible precautions against excessive exposure to the sun and avoid sunburn:

- Wear long-sleeved shirts and a wide-brimmed hat
- Always use a sunscreen with a sun protection factor (SPF) of 30 or more-whether out in the sun at home or abroad
- Sit in the shade when possible.

Always bring to the attention of your doctor or the transplant team if you notice any new or changing moles or unusual spots on your skin.

Screening programmes for cervical, breast and testicular cancer

The detection and treatment of cervical abnormalities through screening programmes can prevent cervical cancer developing.

All women aged between 25 and 50 years should be offered a cervical smear test every 3 years at your GP. Women 50- 64yrs are offered this every 5 years.

Breast cancer is rare in young women but becomes increasingly common from the age of 35 onwards. You should learn to be 'breast aware' from around your mid 20's onwards. You should know what your breasts are normally like by regular self examination which involves checking the appearance of the breasts, feeling for any lumps or thickening, noticing any changes in the shape of the nipple or a discharge from the nipple. If you notice any change, tell your GP without delay.

Women aged 50-70 are invited to attend the breast screening programme every three years and we would strongly recommend that you do this.

We also advise all our patients to participate in the National Bowel Screening Programme every 2 years from 50-74 yrs. This is sent directly to your home from the central screening centre in Dundee.

Testicular cancer is quite rare and the cause is unknown but it can be treated if detected early. All men from puberty onwards should do a regular simple check of their testicles. This will help you to know what is normal for you and make it easier for you to detect any changes such as swelling, a hard lump developing or pain around the testicles.

Osteoporosis is a gradual thinning and weakening of the bones which increases with age. Osteoporosis can cause pain in the bones, often the back, and increases your risk of bone fractures. It is common in people who have had long-standing liver disease and may become worse temporarily after a transplant because of treatment with steroids (prednisolone). Other risk factors include:

- early menopause or prolonged absence of periods earlier in life
- family history of osteoporosis
- thin body type
- lack of exercise
- smoking
- high alcohol intake
- diabetes.

How can I prevent osteoporosis?

Diet and exercise are the main ways of preventing osteoporosis:

- your diet should include plenty of calcium rich foods and vitamin D - the dietitian can give you advice on what to eat to increase your calcium intake
- keep active - exercise appears to reduce bone loss and may stimulate new bone growth. Outdoor exercises such as walking and cycling are especially good.

In addition you should:

- protect your back - lift heavy objects correctly and avoid twisting your body
- stop smoking
- reduce your caffeine intake.

If you are at risk of developing osteoporosis or if you have evidence of thinning of the bones already, the doctors at the Transplant Unit may:

- refer you for a special scan to measure the density of your bones (a DEXA scan)
- recommend medical treatment.

Drinking Alcohol

If alcohol was the cause of your liver disease total lifelong abstinence is mandatory .This is clearly explained throughout your transplant journey to safeguard your future health and commit to the organ donation process after receiving the Gift of Life.



Because alcohol is processed in the body by the liver, many people prefer to remain abstinent from alcohol after their liver transplant. Taking alcohol within the limits of the national guidelines will not, however, damage the new liver providing it is working well and you are in good health generally unless alcohol is thought to have been the cause of your liver disease.

It is recommended that no alcohol should be consumed within the first three months post transplant. This will allow your body to recover from major surgery and enable adequate titration of your immunosuppression medications.

What are the national guidelines?

To keep health risks from alcohol to a low level it is safest not to regularly drink more than 14 units a week.

These national guidelines are for men and women

Examples of alcohol units: 1 bottle of wine = 10 units
1 pint of beer = 3 units

If alcohol was thought to be the cause of your liver disease, total lifelong abstinence is mandatory to safeguard your future health.

Stopping Smoking

Cigarettes are the number one cause of death in Scotland through problems like heart disease and lung cancer. Cigarette smoking after a liver transplant may limit the extent of your recovery and return to fitness. By continuing to smoke you are:

- increasing your risk of chest infections
- increasing your risk of lung cancer
- increasing your risk of high blood pressure
- increasing your risk of having a heart attack or stroke.



You are strongly advised to STOP SMOKING before a liver transplant

Giving up smoking is difficult at any time. Before trying to give up it is worth thinking about why you smoke. Is it:

- out of habit?
- because you need the nicotine?
- to cope with stress?

These are all real reasons - but they are not good reasons for continuing to smoke. Smoking is a habit you can do without. Your body doesn't really need nicotine. There are other ways of coping with stress (in fact nicotine is a stimulant and does not relax your body).

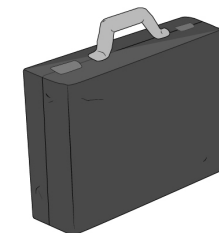
Think of the reasons for giving up:

- feeling in control of your health and body
- reducing your risks of serious illness and disease
- saving money
- becoming fitter and benefitting more from your liver transplant operation.

You CAN stop smoking - help is available. Further information is available from your GP, Practice Nurse or from the Transplant Unit.

Real Life

Going Back to Work



When can I go back to work?

You may return to work anytime from three months after transplant but it is likely to depend on how unwell you were prior to transplant. It is a good idea to begin part-time work and progress to full-time when you feel ready although some people do feel well enough to start work full-time straight away.

Can I go back to my original job after a transplant?

If you have any questions about your return to work or are worried that your job may no longer be suitable for you, please discuss this with the staff at the Transplant Unit. Your employer may require some confirmation as to your fitness to return to your original job and the Transplant Unit can provide this.

What if I am looking for a new job?

Please contact the Transplant Unit if you require any help in support of an application for a new job with regard to your health or liver transplant.

You may feel that employers have a different attitude to you now that you have had a liver transplant. If you experience any problems with employers' attitudes, please speak to staff in the transplant unit who wish to assist your return to work in any way possible.

Driving again after a Liver Transplant

Driving demands physical strength and good concentration - both of which will have been affected by your transplant and stay in hospital.

We recommend that you wait at least six weeks after your transplant operation before starting to drive again. The exact length of time will depend on the speed of your recovery and everyone will regain their strength, concentration and confidence at different speeds.



How will I know if I am ready to start driving?

You must feel that you want to start driving again and begin by practising for a short distance on a quiet stretch of road. You should be able to:

- have the strength in your stomach muscles to lift both feet off the floor and push them down as in an emergency stop
- turn your upper body fully in both directions so that you can put on your seatbelt and see out of the rear window of the car.

What if I had lost my driving license on medical grounds before my liver transplant?

You will need to notify the DVLA and your insurance provider if you wish to reapply for your driving license following your liver transplant. This will only be possible if the symptoms that had caused you to lose your license have improved since your transplant. Your GP can give you more detailed advice on reapplying for your license and assessing your fitness to drive.

Going on Holiday

When can I go on holiday?

This will depend on the country you are planning to visit and the speed of your recovery after your transplant.

You can travel within the UK when you feel well enough and your clinic visits are no longer so frequent. This is likely to be after the first three months.

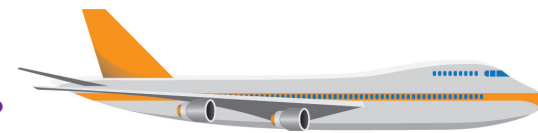
If you are travelling abroad we advise you to wait for one year following your transplant. Please consult the transplant co-ordinators before booking a holiday abroad and plan well in advance as there are a number of important points to consider:

- Travel insurance
- Vaccinations
- Sun exposure and skin protection
- Eating and drinking safely
- Avoiding infection.

What do I do about holiday insurance?

It is very important to notify your travel insurance company that you have had a liver transplant. This may increase your holiday insurance premiums. No matter where you are travelling, always check that your insurance cover is adequate to meet whatever expenses you may incur and will cover the cost of returning you to the UK for treatment.

If you have problems obtaining a reasonable quote for insurance please contact the transplant unit for advice as we can suggest companies who have been helpful in the past.



Travel insurance is your responsibility - do not travel without it!

Can I Sunbathe?

Damaging your skin can, over time, lead to skin cancer. Because of your anti-rejection medication your body is less able to protect itself against the damaging effects of the sun on your skin.

Anyone on anti-rejection medicines is at greater risk and **MUST** take sensible precautions against excessive exposure to the sun and sunburn:

- Wear long-sleeved shirts and a wide-brimmed hat
- Avoid sitting out in the sun between 11am and 3pm
- Sit in the shade when possible
- Check with the medical staff if you notice any new or changing moles or unusual spots on your skin.

Always use a sunscreen with a sun protection factor (SPF) of 30 or more-whether out in the sun at home or abroad.

What if I require vaccinations?

Find out well in advance if you require vaccinations or anti-malarial tablets for your chosen destination. There are some vaccinations which you cannot have because of your medication - these are known as **LIVE VACCINES**.

The live vaccines you are likely to be offered are Yellow Fever and Oral Polio. There is an alternative polio vaccine given by injection if you plan to travel to a country for which you require vaccinations, please discuss this with the medical staff or transplant co-ordinators at the transplant clinic well in advance.

Certain anti malarial drugs can interfere with your medication - do not take any anti-malarial tablets without first consulting the transplant unit.

Can I take my medication out of the UK?

You must have an adequate supply of your medications with you as you are unlikely to be able to get them abroad. Do not put all your medicines in your check in luggage in case your bags go missing. You should always carry a list of your medications with you for example in the form of a repeat prescription.

Further information about travelling abroad after a liver transplant is available from the Transplant Unit.

Sexual Relationships following a Liver Transplant

There are many reasons why you may have concerns about sexual relationships before and after a liver transplant. These concerns may stem from emotional distress, physical changes in your body or from medical problems related to your liver disease and its treatment. Each person will react differently to the changes in their life that a liver transplant brings and as a result, there is no right or wrong time to consider resuming, or starting, a sexual relationship.

There are, however, a number of important points to consider:

- having sex will not harm your new liver in any way
- for women, menstruation and fertility can return quickly after a transplant
- contraception is very important as pregnancy should be avoided for at least one year following a transplant
- for men, sperm production and fertility should not be affected by your transplant or medication. However if you are receiving treatment with Valganciclovir the sperm can be affected, so a barrier form of contraception should be used for the duration of the treatment
- it is important to take steps to avoid infection and sexually transmitted disease.

Is it possible to have a baby following a liver transplant?

There have been a number of successful pregnancies and healthy babies born to liver transplant recipients. Becoming pregnant is only advisable once you have returned to full health - the length of time this will take will vary for individuals but pregnancy should be avoided for at least one year after your transplant.

An important point to consider

Some immunosuppression medication can be harmful to the developing foetus. It is very important for male and female transplant recipients to discuss planning pregnancy. If pregnancy is unplanned it should be discussed as soon as possible with the transplant team with regards to possibly changing some medication. Please discuss breast feeding with the Transplant Team at this time too with regards to immunosuppression.

Can I take the oral contraception pill following my transplant?

Yes, it is generally safe to take the pill in the longer term as a form of contraception. However, the pill has been associated with an increased risk of blood clots (thrombus) and its use should be avoided for three months following transplant. If you have high blood pressure, the pill is not recommended. If you wish to use this form of contraception, please discuss it carefully with your GP who may seek advice from the transplant unit doctors.

If you have any questions or concerns about sexual relationships, contraception and pregnancy following a liver transplant please speak to a member of staff at the Transplant Unit or your own GP.

Any questions?

Should you have any questions or concerns about any aspects of liver transplantation that you wish to discuss with a member of the transplant team, please contact us at the Transplant Unit on:

0131 242 1721

Websites you may find helpful

www.nhslthian.scot.nhs.uk/Services/A-Z/ScottishLiverTransplantUnit/

www.nhsinform.scot

www.getcheckedearly.org

www.bad.org.uk/leaflets

www.nhsinform.scot/bowelscreening

www.gov.uk (DVLA)

www.fitfortravel.scot.nhs.uk

www.odt.nhs.uk

Acknowledgements

The information in this section was collated by the staff of the Scottish Liver Transplant Unit.

Edited by Judith Bennet and Rosanne Bate.

Revised by Patricia O'Sullivan May 2019 Liver Recipient Transplant Coordinator.

Front cover "Members of the Edinburgh Transplant Team proudly displaying their medals at the 25th Anniversary Celebration of the Scottish Liver Transplant Unit".

Booklet design: Medical Photography, NHS Lothian, LK, May 2019
19_05552.

APPENDIX: FOOD SAFETY POST TRANSPLANT

Following a transplant, you will be prescribed immunosuppressant medication to prevent the body rejecting the new organ. As a result of this therapy you have an increased risk of picking up an infection, which could be food-related. It is therefore sensible to follow the advice below to minimize the risk, especially during the immediate few months post-operatively.

Avoid

- Raw or undercooked meats, poultry or fish
- Shellfish
- Unpasteurized milk products. Check the label – if it does not say 'pasteurized', then it is not
- Foods from open delicatessen counters – choose pre-wrapped foods from the chilled counters
- Refreezing or reheating foods.

Ensure

- Fruit and vegetables are washed thoroughly before use. Peel if necessary. Discard decaying foods
- Work surfaces are disinfected after preparing raw meat/poultry and before preparing cooked foods or salads
- Cooked foods are immediately chilled or frozen after use
- Food is defrosted completely and cooked well
- Take chilled and frozen foods home quickly or use a cool bag if there is to be a delay
- Do not eat foods after their 'Use by date'
- Prepare and store raw and cooked foods separately. Make sure meats in the fridge cannot drip onto cooked foods or salad. Store raw food on the bottom shelf. Always re-heat bought, cooked, chilled foods and ready to eat poultry. Make sure it is piping hot.

- Eggs must be thoroughly cooked. Throw away cracked eggs. Keep eggs in the fridge. Avoid foods containing raw eggs.
- In the initial period after your transplant, avoid pate and soft ripened cheeses like Brie, Camembert and blue veined types.
- Use a fridge/freezer thermometer. The coldest part of your fridge should be 0-5°C, and your freezer should be -18°C or below.

Additional Risks

- Contaminated soil and undercooked meat can cause another type of infection called toxoplasmosis. For this reason always wash hands immediately and thoroughly after contact with pets or animals, after gardening and returning from park areas.
- If you have a pet, ask someone else to empty the litter tray or use gloves and wash hands thoroughly.
- Always keep animals out of the kitchen area.

Notes:

[illegible]