Going Home - your questions answered

Everyone looks forward to going home but it can be an anxious time. Your discharge is carefully planned by the team so that you and your family feel confident and well supported at home. You will receive a Discharge Information Pack at this time and regular follow up will be arranged.

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.

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IN THE BEGINNIG

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 green 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 within a few days of leaving hospital so he can renew your prescription before your seven day supply runs out.

The Transplant Unit pharmacist will make arrangements with your local chemist if they think you will have difficulties in obtaining any of your medicines outside the hospital. You may find it better to stick to one pharmacy so that they always have your tablets in stock and have a record of your medicines if you have any queries.

Do I need to pay for my medicines?

You are not exempt from prescription charges even although you have to take immunosuppressant medication every day for the rest of your life. You may, however, be exempt for some other reason e.g. if you are diabetic or are on a low income.

What about a pre -payment certificate?

If you are not exempt from prescription charges then an annual prepayment certificate is the most economical way of paying for your medicines. Please ask at your local chemist or post office.

Is it safe to take other medicines?

Other medicines may interfere with your Tacrolimus / Cyclosporin.

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 / cyclosporin 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 forget to take a dose of any of your medicines, do not take twice the usual amount when it is time for your next dose. Continue with your normal dose when it is next due.

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.

Diet

After a successful liver transplant your appetite and dietary requirements should gradually return to normal. Although your liver disease may have left you undernourished there is often a problem with becoming overweight after your transplant. You should not need a special diet for home but this is a good time to think about your general health and take positive steps to improve it. Eating healthily is one step you can make towards improving your health but what does it involve:

What is healthy eating about?

- it is about enjoying a variety of foods and understanding how the food we eat affects our health
- it is about cutting down on fat, sugar and salt and eating more fruit and vegetables

- it is not about losing weight or restricting what you eat but rather about making gradual changes to your eating pattern that become part of your lifestyle
- it is about eating the right amount to be a healthy weight for your height
- a healthy diet means you can have occasional treats just not too many!

Healthy eating means eating a balance of food from the following food groups: **Starchy foods**: Eat plenty of bread, potatoes, cereal, pasta and rice including wholegrain varieties (avoiding lots of butter and fattening sauces!)

Fruit and vegetables: Try to eat 5 portions of fruit and vegetables every day; This may sound a lot but could include 2 glasses of fresh fruit juice, a banana, a portion of salad in your sandwich at lunch and a serving of freshly cooked vegetables with your evening meal.

Milk and dairy produce: choose lower fat types eg. semi-skimmed milk **Fats**: use low fat alternatives to butter and margarine where possible and avoid using fat to cook food

Sugar and sugary food and drinks: limit your intake of sugary foods to an occasional treat - choose diet / low sugar varieties where possible

Alcohol: it is possible to take alcohol within the limits of the national guidelines. However if alcohol is thought to have been the cause of or contributed to your liver disease, lifelong abstinence is necessary to safeguard your future health. Remember that alcohol is high in calories and may contribute to weight gain.

Will I have any special dietary requirements

Before you are discharged from the Transplant Unit, the dietitian will assess your food intake and your weight and discuss with you any specific dietary requirements you may have.

Do I need to take supplement drinks at home?

If your appetite is poor and are you are not managing to eat well after your transplant, you may be advised to continue taking the supplement drinks. The dietitian can arrange for these to be prescribed at home for you until your appetite and food intake have improved.

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 a transplant.

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

What about other dietary restrictions?

Other restrictions such as protein and fluid restrictions tend to be temporary. It is unlikely you will need to continue on them after discharge - the dietician will keep you advised but if in doubt, please ask.

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 increased appetite. As a result, you will gain weight but this should not be excessive.

What can I do to prevent excess weight gain?

Before you go home, the dietician will calculate your target weight and weight range. and provide information on healthy eating and preventing weight gain. Remember that increasing your activity level and doing gentle exercise is very important in preventing excess weight gain. If you are concerned about weight gain, please ask to speak to the dietician at your next clinic visit.

How can I contact the dietitian?

If you have any concerns about your diet please contact the dietitian either at your next clinic visit or through the Transplant Unit at any other time. If necessary, a community dietitian can visit you at home. This would be arranged by the Transplant unit dietitian.

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- 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:

- 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.

Exercise should make you feel GOOD!

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 got worse 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 e.g. 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 Others

Sex

There is no medical reason that you cannot have sex when you feel well enough. However, you may find that it takes some time for your sex drive to return and this is guite normal.

Contraception/ pregnancy

Female patients of child bearing age must use appropriate birth control methods as pregnancy should be avoided for at least a year after liver transplant.

Driving

You may start to drive about six weeks after discharge from hospital unless otherwise informed by DVLA.

Returning to work

You are likely to remain off work for at least three months but this depends on your recovery and the type of work you do.

Travel

There is no reason to prevent you from travelling in the UK as soon as you feel well enough but you will have to discuss overseas travel with the Transplant Unit for information on health risks, travel insurance, medication etc.

General Health Screening

Prevention is better than cure. It is essential to follow advice on cancer screening for example skin protection, cervical screening, breast or testicular self examination.

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 2065

FOLLOW UP CARE

- Clinic Follow-up
- Travelling to the Royal Infirmary
- Prevention and Screening

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 and the nurse will:

- discuss your current health, check your weight & blood pressure
- examine your wound
- 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/ cyclosporin before coming to clinic. Bring it with you to take after you've been seen.

Re-admission to the Transplant Unit

If you are unwell, we may have to re-admit you to the unit from clinic for further investigations and treatment.

Following clinic, if your blood results are abnormal we may phone you to alter the dose of your medications or to arrange for you to be readmitted to the unit for further investigation or 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.

discharge to 6 weeks	1 - 2 weekly	Transplant Unit	Tuesday- am
6 weeks - 3 months	2 weekly		
3 months - 6 months	4 - 6 weekly	Outpatient Department (OPD1) at the New Royal Infirmary	Thursday- am ,
6 months - 1 year	every 2 months	OPD1 and local hospital	
after 1 year	3- 6 monthly	alternate visits between MOPD and local hospital	

Who will I see at clinic?

Tuesday	Thursday	Always available- please ask if you wish to speak to any of the following staff:
Transplant Hepatologist	Transplant Consultant	Dietitian
Transplant Surgeon	Transplant Registrar	Physiotherapist
Transplant Co-ordinator	Transplant Co-ordinator	Social Worker
		Pharmacist

The transplant co-ordinators are present at your 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.

Will I need any other tests as part of my follow-up care?

Colonoscopy - if you have had liver disease associated with ulcerative colitis then you will require a colonoscopy examination every year. This can be performed at the Royal Infirmary or at your local hospital.

Ultrasound scan - if you needed a liver transplant because of a tumour (cancer) in your liver then you will require an ultrasound scan every 6 months - 1 year after your transplant.

Liver biopsy- if you needed a transplant because of Hepatitis C infection then the present practice is to perform annual biopsies.

Travelling to the Royal Infirmary

Travelling to the Royal Infirmary after your discharge from hospital can be time consuming and expensive. Not everyone is entitled to help with travelling costs and hospital transport is usually only available to those in need.

Am I entitled to travelling expenses?

assistance with travelling expenses is only available if you:

Receive Income Support - this entitles you to full reimbursement of your costs **Have a HC2/HC3 certificate of low income** - this is for people whose income is higher than the Income Support level but still low and entitles you to reimbursement of some or all of your costs

Live in the Highlands and Islands - your travel is arranged by the local health board who cover most of the cost

Receipt of any other benefit does **not** automatically entitle you to assistance with travel costs

How do I claim travelling expenses?

Ask the clinic nurse for a **Certificate of Attendance** which will cover the cost of your return journey for you and an escort (if required).

Take this form together with proof of eligibility (either your Income Support book or number, or your HC2/HC3 certificate) to the Hospital cashier, who will then reimburse your costs.

If you have any queries the Unit Social Workers will be pleased to advise you.

Prevention and Screening

- Skin Protection
- Screening Programs
- Osteoporosis
- Hormone Replacement Therapy
- Drinking alcohol
- Stopping Smoking

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

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
- Avoid sitting out in the sun between 11am and 3pm
- Sit in the shade when possible

• Always use a sunscreen with a sun protection factor (SPF) of 15 or more - whether out in the sun at home or abroad

Check with the transplant unit medical staff or your GP 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 20 and 64 years should be offered a cervical smear test every 3 years at your GP.

We advise women on immunosuppressant medicines to attend the GP for a smear once a year i.e. more frequently than the regular screening programme.

Your GP or practice nurse can arrange this for you. 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 - 64 are invited to attend the breast screening programme and we would strongly recommend that you do this.

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.

Further information on skin care, screening programmes and self examination for cancers is available from your GP, practice nurse, well woman / well man clinic or from the transplant unit.

Osteoporosis

Osteoporosis is a gradual thinning and weakening of the bones which increases with age. Osteoporosis can cause pain in the bones, often in the back and increase 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

Hormone Replacement Therapy

Many women benefit from taking hormone replacement therapy (HRT) to treat symptoms of the menopause. HRT reduces the risk of osteoporosis and heart disease.

Is it safe to take HRT?

After a transplant it is safe to take HRT if your new liver is working well. This is important because the liver is involved in processing hormones in the body. HRT can be started six months after your transplant.

If you wish to take HRT please discuss this with the Transplant Unit doctor who can advise your GP.

Drinking Alcohol

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

What are the national guidelines?

There are national guidelines on the number of units of alcohol that it is safe for men and women to drink. These are:

- men up to 4 units maximum per day
- women up to 3 units maximum per day
- 1 unit of alcohol
 - = 1 small glass of wine
 - \circ = 1 half pint of beer
 - = 1 pub measure of spirits

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 infection
- 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 after 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 benefiting 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**

HELP !

Although they are not directly involved in your care, the transplant coordinators follow your progress as you recover in the unit after your transplant.

Going home after your transplant can be an anxious time but please remember that you can contact the transplant co-ordinators if you have any questions or concerns. They are available to talk to you and your family about any aspect of your operation or transplantation and organ donation in general.

It is quite natural to have thoughts about the donor of your new liver. This can happen very soon after your operation but may not be until many months or even years have passed. It can help to discuss these thoughts - the transplant coordinators are there to listen and can help you write a note or card to the family of the donor.

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.

Social, financial & personal support

The aim of the Transplant Unit Social Workers is to work with you to achieve as high a quality of life as possible following your liver transplant covering:

- your period of recovery
- the steps towards independence
- re-establishing a positive lifestyle

The service is for yourself and your family/carers.

Social workers have a particular role when children's interests are being considered.

The service may include support, advice, information, access to counselling and liaising with other services.

Brief notes are kept on contact which are open for you to see.

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
- 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, any situation where there may be concerns about the well-being of children.

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
- Prescription charges
- 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.

Employer's attitudes to your liver transplant may be a concern - the social workers can provide information and discussion that may help.

What can I do if I am having difficulty coping?

As you progress towards independence, there may be times when you need to discuss more personal aspects of your experience of illness and recovery, e.g. if you are finding that it is taking you longer to become physically independent than you had expected, or generally adjusting to changed circumstances.

Family, yourself and friends may be affected at different times, and in different ways. The social workers aim to offer support in a way which suits individuals.

How can I contact the social workers?

The social workers can be contacted via the Transplant Unit Monday- Friday, 9.00am- 5.00pm.

They can be available out with these hours by arrangement.

The Social Work office is in the Unit and staff can direct you to it.

The social workers can see you at the Outpatient Clinic if you wish.

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 telephone number of the Chaplain's Office is 0131-5363087.

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 For example the common cold, chicken pox, flu, glandular fever
- you should get the flu vaccination each winter from your GP
- always wash your hands after going to the toilet
- always wash your hands after changing a baby's nappy or handling any human 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 sorts 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 your GP for a prescription of Acyclovir (an anti-viral drug). 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 cyclosporin/tacrolimus and 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 cyclosporin / tacrolimus before you start the course.