NHS
The Leeds
Teaching Hospitals
NHS Trust

Liver Transplantation
Book 3

Information for patients

Leeds Liver Unit

Welcome to book 3. This book aims to educate, support and keep you healthy following your liver transplant and for the years ahead.

‘My transplants gave me a new chance at life and also the gift in gratitude in all I do, from no hope to touching the stars, every day I wake I smile’

‘My gift has enabled me to live again instead of just existing’

‘I made it to my son’s wedding which nobody really expected and got to watch all three of my boys grow into men’

‘My transplant has changed my life from being confined to my bed in chronic pain with no quality of life at all, to a life shared with my family, planning holidays and volunteering in my community’

‘My transplant has given me my life back - A life that I’d forgotten existed’

Contents

Cardiovascular disease

After your liver transplant you are more at risk of developing cardiovascular disease (angina, stroke, heart attack).

- During your annual review we will discuss your risk of cardiovascular disease.

For further information on how to reduce your risk:

- **www.nhs.uk/conditions/high-cholesterol**
- **www.heartuk.org.uk/health-and-high-cholesterol**
- **www.bhf.org.uk/heart-health/risk-factors/high-cholesterol**
- **www.nhs.uk/conditions/statins/**

Hypertension (high blood pressure)

It is quite common for people who have had a liver transplant to develop high blood pressure.

During each clinic appointment your blood pressure (BP) will be measured. We aim for a blood pressure of approximately 135/85mmHg.

As people's blood pressure is often high in clinic, we will sometimes ask your GP to help monitor your blood pressure.

Treatment for hypertension

Treatments to reduce your high blood pressure include making changes to lifestyle factors, such as:

- Weight loss

- Increase in regular exercise
- Maintaining a healthy diet
- Stopping smoking

Medication

You may require medication to lower your blood pressure following your liver transplant.

For further Information:

www.nhs.uk/conditions/high-blood-pressure-hypertension

www.bhf.org.uk

Diabetes

After your liver transplant you are at a higher risk of developing diabetes.

Testing for diabetes

A blood test (HbA1c) will be checked when you attend the clinic. If this is outside the usual range, we will ask your GP to assist with monitoring your HbA1c level and start treatment for diabetes if required.

Preventing diabetes

It is important to take steps to reduce the risk of diabetes.

These steps include:

- Eating a healthy diet.
- If you are overweight, increasing exercise and losing weight will help.

For further information:

www.nhs.uk/conditions/diabetes

www.diabetes.org.uk

Contraception and safe sex

Many people who have had a liver transplant have had safe and successful pregnancies. However, both your surgery and your medicines can have an impact on having a baby.

It is safest to plan a pregnancy with the support from the liver transplant team.

If you are a female patient, there is a risk of birth abnormalities and complications if you were to have a baby whilst still taking mycophenolate. It is recommended that you use **TWO** forms of effective contraception whilst taking mycophenolate.

There are alternatives medicines to mycophenolate that we can use in liver transplant, so if you are taking mycophenolate, it does not necessarily mean that you should not have children. We may be able to switch you onto something else.

You will need to continue to use **TWO** forms of effective contraception for **SIX WEEKS** after switching before you should consider having a baby. This is why it is important to involve you liver transplant team early on when you decide you want to start trying for a baby.

If you are a male patient taking mycophenolate, there is a theoretical risk that there may be complications if you father a child. The available evidence does not indicate an increased risk of malformations or miscarriage in pregnancies where the father was taking mycophenolate, but there is insufficient evidence to rule out any risk. Male patients or their untreated female partner must use reliable contraception during mycophenolate treatment and for at least 90 days after stopping treatment.

Although there are alternative medicines that you can be prescribed in place of mycophenolate, your doctor will discuss with you the risks of complications in pregnancy versus the risk of changing your immunosuppression to your transplanted liver. Irrespective of the method of contraception, the importance of practising safe sex to minimise the risk of acquiring sexually transmitted diseases as well as protecting against unplanned pregnancy when taking mycophenolate is an integral part of your long-term health post-transplant.

Following liver transplant, sexual function and libido can be affected. This can be as result of the medication you are taking alongside other factors such a diagnosis of diabetes, previous excess alcohol use, other factors such as mood, on-going illness and issues with body image. Please discuss any issues or concerns with your post-transplant Clinical Nurse Specialist and your GP.

Medication can be used and prescribed to help with sexual function. Your GP can also assist with further local referrals as needed.

Skin cancer

Skin cancer is the most common cancer in individuals who have received an organ transplant.

You are up to 70% higher risk of developing skin cancer than someone who has not received a transplant.

Increased risk is due to the immunosuppression you take to suppress the body's immune system to prevent rejection of your transplanted liver.

During your 3 months+ and annual review the post-transplant Clinical Nurse Specialist will discuss sun protection to help reduce your risk of developing skin cancer alongside the importance of skin surveillance. A review either by a local dermatologist or GP on an annual basis is advised due to the increased risk of the development of skin cancer post-transplant.

Tips to help in limiting the risk of skin cancer

- Apply a broad-spectrum sunscreen with a sun protection of factor 50. (from March-October).
- Make sunscreen a part of your normal routine.
- Clothing provides excellent protection from sun damage.
- Wear a wide brimmed hat and sun glasses with UV protection.
- Limit sun exposure (no sunbathing) during the hottest sun.
- Having 20 minutes sun exposure in the coolest (early morning sun) can help to increase your stores of Vitamin D, following this sun cream must be applied.

Checking your skin regularly (each month) is advised and asking someone to look at the places you can't see for changes in or new growths such as pink spots or patches, scaly growths, bleeding areas or changes to existing moles will help to prevent/ catch any issues early.

For further information:

- **www.BAD.org.uk**
- **www.nhs.uk/conditions/melanoma-skin-cancer/treatment/**
- **www.dermnetnz.org/lesions/keratoacanthoma.html**

Smoking

Following your liver transplant, it is particularly important that you do not smoke.

Having a transplant puts you at even higher risk of health problems associated with smoking such as heart disease and cancers.

If you continue or restart smoking the chances of you still being alive 10 years after your transplant are significantly lower, compared to people who have either never smoked, or who stopped before their transplant.

If you are smoking, there is a good range of support available to help you to stop, and the liver team can refer you to smoking cessation services.

It is fine to use Nicotine Replacement Therapy if you need to, and this can be prescribed for you by your GP or your local cessation service.

These sites provide several useful resources to support you in stopping.

- **www.yorkshiresmokefree.nhs.uk**
- **www.nhs.uk/smokefree**
- **www.oneyouleeds.co.uk**

Alcohol

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

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

- The medication that you need to take after your transplant to stop your body rejecting your new liver may make it more difficult for your liver to break down the alcohol, so relatively small amounts can damage it quite quickly.
- It is possible that if you have drunk too much in the past, you may be unable to stick to low levels of alcohol use and you may find that you return to drinking at potentially harmful levels very quickly.
- Unfortunately sometimes when people start to drink alcohol again after their transplant it may be that they do not keep their appointments or take their medication. This will have a harmful effect on your new liver.

It is also very important that you continue to avoid alcohol in food and that you do not use products such as mouthwashes that contain alcohol. You should also continue to avoid ‘alcohol free’ beers, wines and ciders, as we know that people who drink these types of products are more likely to return to drinking and are also at much higher risk of consuming alcohol by mistake.

If you are having thoughts about drinking, or you are concerned that you may drink, the alcohol team are available for you to contact for support and advice, even if it is many years after you had your transplant.

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

Drinking alcohol after a liver transplant, whatever the underlying liver disease is **NOT** recommended, as having to break down alcohol causes extra strain on your liver, which is best avoided. Your liver breaking down alcohol can speed up and exacerbate the damage caused by the underlying condition. Medication given to prevent your body from rejecting your new liver also makes it more difficult for it to break down the alcohol.

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

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

Illicit drugs

It is important that you avoid taking any illicit substance after your transplant, as these could have unpredictable consequences. They may interact with your prescribed medication, possibly leading to damage in your new liver. if you have any concerns or questions about this, please speak to the substance misuse nurse.

Nutrition after Liver Transplant

As you recover following transplant, your body's requirement for protein and energy slowly reduce. Your new liver stores energy normally and snacks between meals or before bed are no longer necessary. You will get an idea of whether your body's nutritional requirements are returning to normal by doing some simple self-monitoring;

- Monitor your physical ability.
- Weighing yourself is sensible, if you have any concerns please discuss this at your next clinic visit.

Following liver transplant, we know that many patients gain weight. There are a few reasons for this;

- Steroids can increase your appetite.
- Snacking habits are hard to change.
- As you recover your body needs fewer calories and less protein.
- Physical activity levels are not yet back to normal.
- For patients who were losing weight (dry weight, not fluid) or muscle mass pre transplant, there is a desire to get back to your 'normal' weight quickly.

All these things can cause weight gain, and often it is fatty tissue that is increasing, not muscle. You have already been told about the raised risk of cardiovascular disease and diabetes after transplant, and these can both be caused by being overweight. Non Alcoholic Fatty Liver Disease is another condition which can be caused by being overweight, and if this developed in your new liver it could be more difficult to manage than in a person who has not had a transplant.

These are some of the reasons why it is important to ensure you are as close to a healthy weight as you can be.

The easiest way to tell if someone is overweight is to calculate their BMI or Body Mass Index. This number compares a person's weight to their height. You may already know your BMI from your appointments with your nurse, doctor or dietitian. If not you can work out your BMI using the equation below or you could type 'BMI calculator' into a search engine on the internet. The ideal BMI is between 20-25 kg/m^2. If your BMI is higher than this, it may be recommended to work towards weight loss.

Body Mass Index is your weight divided by your height squared:

Body Mass Index = Weight (kg) ÷ Height^2

Weight loss

Try to lose weight slowly and steadily, making changes that can become part of your lifestyle and are easy to continue as you get used to them. ‘Crash’ diets tend to result in quick weight loss followed by re-gain, and people can weigh more after the diet than they did initially.

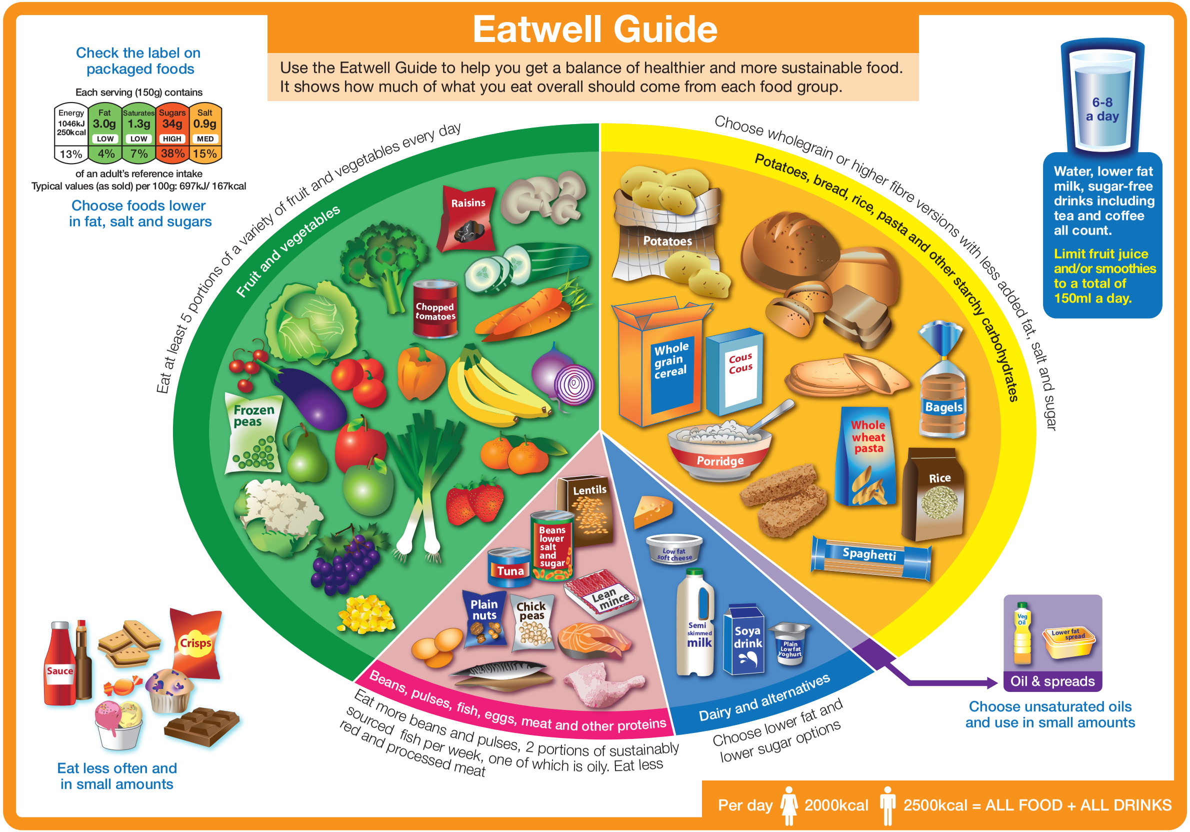
It’s important to remember that if you were advised to have a 50g carbohydrate snack before bed prior to having your transplant, this does not need to be continued.

Below are some suggestions for how to start to make changes to reduce your weight:

- Reduce fat in the diet, as fat and fatty foods contain a lot of calories in small amounts. Saturated fats are a type of fat that can increase your risk of cardiovascular disease. Saturated fats are usually solid at room temperature and are often from animal sources. Foods with a high saturated fat content include butter, lard, ghee, coconut oil, hard cheese, cream, fat on meat, skin on chicken, cakes, biscuits and desserts.
- Reduce the sugar you use, and sugary foods such as cakes, biscuits, sweets, and chocolate.
- Choose Lower fat cooking methods such as grilling, baking and boiling.
- Aim for no more than 3 portions of fruit per day, eat plenty of vegetables.

- Cut out sugary drinks, reduce sugar in tea and coffee, do not have more than 150ml fruit juice per day, don’t drink milk throughout the day.
- Try to increase your physical activity.
- Make sure you are not still taking supplement drinks e.g. Fresubin, Fortisip or Ensure, if you are no longer prescribed these.
- Reduce your portion sizes - use a smaller plate or bowl and serve food on individual plates rather than helping yourself at the table.
- Choose high fibre versions of foods which are more filling, such as wholemeal or brown bread, pasta and rice.
- Shop from a list and avoid shopping when you’re hungry.

Eatwell Guide gives you an idea of how the different food groups should be balanced within your diet



Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

Check the label on packaged foods

Each serving (150g) contains

Energy	Fat	Saturates	Sugars	Salt
1046kJ 250kcal	3.0g	1.3g	34g	0.9g
	LOW	LOW	HIGH	MED
13%	4%	7%	38%	15%

of an adult's reference intake
Typical values (as sold) per 100g: 697kJ/ 167kcal

Choose foods lower in fat, salt and sugars

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

Fruit and vegetables

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

Potatoes, bread, rice, pasta and other starchy carbohydrates

6-8 a day

Water, lower fat milk, sugar-free drinks including tea and coffee all count.

Limit fruit juice and/or smoothies to a total of 150ml a day.

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

Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat

Dairy and alternatives

Choose lower fat and lower sugar options

Oil & spreads

Choose unsaturated oils and use in small amounts

Eat less often and in small amounts

Per day 2000kcal 2500kcal = ALL FOOD + ALL DRINKS

Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

You can be referred to the Liver Dietitian at St James' Hospital for weight management advice, or you could see a Dietitian or access an NHS funded weight management service closer to home. If you wanted to discuss any of these options, you could speak to any of the professionals you see in Post-Transplant Clinic, or to your GP (contacts at the back of this book).

Food safety advice

When you are 6 months post-transplant, you might be able to stop following the ‘Food Safety’ advice you were given after transplant. You should discuss this at your Post Transplant Clinic appointment around that time. **If you are taking less than 4 immunosuppressive medications and are on less than 10mg of prednisolone you will probably be told that you can reintroduce most of the foods, you were avoiding.** You could therefore start having mineral water, blue and soft cheeses, rare beef, rotisserie chicken, smoked salmon and live yoghurts, among other foods.

Every transplant patient should be careful when consuming foods which are linked to Hepatitis E, a virus which affects the liver.

After 6 months you can consume shellfish but only if it is bought from a trusted retailer (e.g. a supermarket) and the product shows a visible use by date. Ensure that shellfish is cooked until piping hot.

Do not consume shellfish after the use by date and you should avoid all uncooked and undercooked shellfish including prawns, crayfish, shrimp, langoustines, mussels, clams, scallops, oysters, scampi and lobster.

You should avoid all undercooked venison and processed pork. This includes pork that has been undercooked accidentally such as sausages on a BBQ and also pork that is cured rather than cooked for example salami, Parma ham or chorizo. Adding cured pork meats to a pizza and cooking it at a high temperature or cooking them in a dish such as a stew are a good way to enjoy these flavours.

You must also continue to avoid grapefruit (including juice), Seville oranges and pomelo which interact with Tacrolimus (Adoport, Advagraf)

Strengthening exercises

As well as doing cardiovascular work, it’s important to work your muscles harder than usual against some form of resistance. In turn this can help improve your balance and co-ordination.

At 3 months post-transplant, your wound should be healed, and it is safe for you to start these exercises now. Exercises can be done with hand weights, machines, TheraBand or household equipment such as lifting cans of food or bottles of water. It is safe for you to go to the gym and use weight stations.

As with cardiovascular activity it is important to discover what you are able to do, set yourself realistic targets for your exercises.

Start off with very gentle weights and low repetitions e.g.: 3 sets of 8, progressing by first increasing the number of repetitions that you can do, then the weights that you are lifting.

Stomach exercises

Because of your incision your stomach muscles will have become weaker. Even simple techniques such as tightening your tummy muscles and being aware of your posture and not slouching can improve the strength of these abdominal muscles. If you are keen to do sit-ups and more advanced abdominal exercises you need to wait 4 months post-surgery until this is safe.

Contact sports

These should generally be avoided but individuals can discuss this with a doctor.

Exercise in the community

If you are happy exercising regularly by yourself, keep this up. However, if you feel that you would like more support / guidance there are a variety of ways to access this in the community.

Below are some recommendations:

1. **'Exercise on Referral'** is a specific and formalised fitness programme which can be completed in the community. Qualified instructors will supervise you over a 12-week period to help you get back into fitness following your operation. Visit your GP to discuss this and they may be able to make a referral
2. The website NHS Choices provides information on the benefits of being more physically active as well as guidelines and tips on how to include physical activity and exercise into your day. The website includes simple strengthening exercises you can do at home.
   Visit **www.nhs.uk** to find out more.
3. Ramblers run organised walks to help people across the country lead a more active lifestyle.
   Visit **www.ramblers.org.uk** to find out more information and to find organised walks near you.

Important advice

Work at your own pace and listen to your body, work within your own limits. Be prepared to accept that on some days you are capable of doing more than on other days.

Don’t exercise if you are feeling unwell. Don’t continue with any exercise that causes you discomfort or pain.

You could be eligible for the transplant Games.

Keeping active

Cardiovascular exercise

At 3 months after your transplant, your body is recovering well, and you should be noticing that the pain from the wound has reduced.

Ideally you should already be doing some activity such as walking regularly, using a treadmill or using a static bike. This is known as cardiovascular exercise, or physical activity which is designed to improve how efficiently your heart and lungs work. It can be classed as light, moderate or high.

- **Light intensity means that you are breathing and talking easily without much effort.**
- **Moderate intensity means that your heart beats slightly faster but is not racing and your breathing rate is a little faster and deeper, yet you can still comfortably talk, (such as you would feel if you went for a brisk walk).**
- **High intensity is more intense where you are breathing very hard so that you can’t carry on a conversation and your heart beats very fast.**

Current UK Department of Health guidelines recommend 2.5 hours of moderate physical activity (150 minutes) or 1.5 hours (75 minutes) of high intensity physical activity per week. This can be broken down to 3x10 minute sessions per day, 5 days a week.

Recommendations also include additional muscle strengthening / resistance exercises on 2 of the days. (see below).

Remember that being active doesn’t mean that you have to exercise intensely. Even small amounts of activity can be beneficial.

Put very simply:

Reduce the time that you sit still. Move more (10,000 steps a day can help you to keep on target).

There are other types of cardiovascular exercise that you may prefer to do rather than going to the gym. Activities such as gardening, dancing, cycling and even household chores such as housework, washing the car and DIY are classed as physical activity.

With physical activity you may not be achieving the recommended targets yet but aim to do so. Start off gently and listen to your body, over time you should see a gradual improvement in what you can achieve. Progress as you can and monitor your improvement by aiming to spend more time at an activity or doing a set activity such as walking/cycling in a faster time or going a further distance in the same time.

The British Transplant Games

The British Transplant Games have been held annually since 1978 and have visited many host cities around the UK including; Leeds, Portsmouth, Newcastle, Edinburgh, Belfast and Sheffield. The Transplant Games aim to encourage transplant patients to regain fitness, whilst increasing public awareness of the need for more people to join the NHS Organ Donation Register and discuss their wishes with their families.

Leeds Adult Transplant Sport Team

The Leeds Team has been competing for many years and currently has over 90 active team members and supporters - one of the largest teams at the Transplant Games!

Although only transplant recipients can compete in the Games, anyone can join the team in a supporting role and supporters/donors can participate in many events.

The Leeds Adult Transplant Sport Team helps a wide range of transplant recipients to take part in sport, build friendships and celebrate the gift of life. It is a network of inspiring, resourceful and courageous people ranging from 18 to 83 years of age who take part in a variety of sports (for fun and for competition), social activities, fundraising and charity events.

We’d love you to join the team

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

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

Email: leedsth-tr.transplantgames@nhs.net
Facebook: www.facebook.com/leedsadulttransplantsport

Travel

If you are planning to travel abroad, we recommend that you take a copy of your last clinic letter. This is in case you need medical attention whilst away. It will contain information about your liver transplant along with details about your immunosuppression. We strongly advise that you have travel insurance. Details of travel insurance companies can be found on: **www.stjamesltsg.org.**

Make sure that you plan ahead and enquire about any vaccinations you may need to go to the country you are planning on. The best person to advise on this is your GP as he will have access to resources that state which vaccines you will need for the area you will be visiting.

Please be aware that some vaccines you need to travel to certain areas will be **LIVE** vaccinations and you **CANNOT** have these. Please see the vaccines table for a full list of these.

If there is no alternative to the live vaccine that you require then you should discuss the risk of traveling to this area with your liver team. Most vaccination schedules need to be given over several months to be effective so please plan this well in advance of your travel date.

When you do travel, make sure you take adequate amounts of your medication with you. Remember to take enough to last in case you get delayed and always split your supply across your hand luggage and hold luggage.

Vaccinations

Following liver transplant, it is important that you do not have live vaccines as they contain a small amount of the live organism and due to the immunosuppression you take following your liver transplant it is possible you could develop an infection from the vaccine.

Flu Jab - You should receive this every year.

Pneumococcal - You should receive this every 5 year.

Permitted Vaccines	
Diphtheria	Typhoid
Tetanus	Pertussis
Tick Borne Encephalitis	Meningococcal
Hepatitis B	Cholera (oral-combined with recombinant B sub unit)
Hepatitis A	Japanese encephalitis
Influenza	COVID-19 (Oxford/Astra Zeneca, Pfizer/BioNTech and Moderna)
Pneumococcal	Inactivated shingles vaccine (Shingrix)
Inactivated (injected) Polio (Salk)	
Haemophilus Influenza B	

Vaccines not to be given	
Polio (oral) Smallpox (vaccinia) Tuberculosis (BCG) Typhoid (Oral-Ty21a) Yellow Fever	Measles, mumps, rubella (MMR) Varicella (chickenpox) Nasal influenza vaccine (Fluenz Tetra) Rotavirus Live shingles vaccine (Zostavax)

If any doubt, please ask.

General health screening

As a post-transplant patient, you are at an increased risk of developing cancers, therefore we encourage you to engage in the national screening programmes offered via the NHS/ GP practices.

It is also important that following a liver transplant you perform regular self-examination of your breasts if you are a Male/Female and of your testicles if you are a male. If you identify any abnormalities, please arrange an appointment with your GP to review the abnormality and arrange further follow up.

The table on the next page details the ages of when national screening should take place, for further information:

www.nhs.uk/conditions/nhs-screening

Table of general health screening

Abdominal Aortic Aneurysm Screening (Offered to all men over 65 years)
Annual Colonoscopy (PSC patients with IBD yearly colonoscopy)
Bowel Screening • 60-74 years old (automatic invite) for home screening Faecal occult blood testing kit • If over 75 years you can request this to continue by phoning **0800 707 6060**
Breast Screening • Breast self-examination regularly Mammogram Screening offered to women aged 50-70 years • 50-53 years old 1st mammogram automatic call • 3 yearly until age 70 Over 70 years - 3 yearly if patient requests
Cervical smear • 25-49 - Screening 3 yearly • 50-64 - Screening 5 yearly Over 65 - Only women who haven’t been screened since aged 50 or those who have recently had abnormal test

Immunosuppression medication

After your transplant, the pharmacy team will have discussed your medicines with you. Over time, some of your immunosuppression medicines may change. Here are a few important points to remember about each of the immunosuppression medicines we use.

On the morning of clinic remember not to take your dose of tacrolimus/ciclosporin/sirolimus before clinic. Bring it with you and have it after your bloods have been taken.

- If you do take it before clinic by accident, let your transplant team know. This way they will be able to better understand why your tacrolimus level may come back high.
- If you accidentally take the wrong dose or brand of medication then contact your transplant team for advice.

Tacrolimus

- Tacrolimus comes in several brands and you should stay on the same brand and take at the same time every day, either once daily (Advagraf and Dalliport) or 12 hours apart (Prograf and Adoport).
- Common side effects of tacrolimus that you may experience long term whilst taking this medicine include altered kidney function, hair loss/thinning, high blood pressure and high blood sugar. If you are worried about any of these please do speak to your transplant team. For more information on side effects see the leaflet that comes in your tacrolimus pack or speak with your transplant team.

Ciclosporin

- Ciclosporin comes as several different brands. The brand that we currently use at Leeds is Neoral® and is taken twice a day.
- It is important that you remain on this same brand. There are instances when we may change this brand but that will be done by your transplant team at Leeds. **If anyone else like your GP switches it you MUST let us know.**
- Common side effects of ciclosporin that you may experience long term whilst taking this medicine include altered kidney function, increased hair growth, high blood pressure, swollen gums and high blood sugars. If you are worried about any of these please do speak to your transplant team. For more information on side effects see the leaflet that comes in your ciclosporin packs or speak with your transplant team.

Mycophenolate Mofetil

- Your transplant team may refer to this as MMF for short.
- You will usually take Mycophenolate TWICE a day but sometimes your transplant team may ask you to take it once or three times a day.
- Take mycophenolate mofetil at the same time each day.
- Common side-effects of mycophenolate include upset stomach, especially diarrhoea and higher risk of infections. If you are worried about either of these please do speak to your transplant team. For more information on side effects see the leaflet that comes in your mycophenolate pack or speak with your transplant team.

- Mycophenolate mofetil is available as several different brands. It is ok to switch between these brands but if you are concerned please do contact your transplant team.
- **Unless you are advised by your transplant team, you must NOT switch between mycophenolate mofetil and mycophenolate sodium (See below).**

Mycophenolate Sodium

- You will usually take Mycophenolate Sodium TWICE a day but sometimes your transplant team may ask you to take it once or three times a day.
- Mycophenolate sodium comes as two different brands, Myfortic® or Ceptava®. It is ok to switch between these two brands.
- **Unless you are advised by your transplant team, you must not switch between mycophenolate mofetil and mycophenolate sodium (See above).**

Azathioprine

- Take azathioprine ONCE a day at the same time every day.
- Take azathioprine with food as otherwise it can upset your stomach.
- Common side effects of azathioprine include risks of infections, upset stomach especially feeling sick and hair thinning/loss. If you are worried about any of these please do speak to your transplant team. For more information see the leaflet that comes in your azathioprine pack or speak with your transplant team.

Prednisolone

- Most patients will have prednisolone stopped within 3 months of their transplant. Some patients may continue on a small dose long term and others may have it restarted.
- **Take prednisolone ONCE a day at the same time each day.**
- It is best to take prednisolone in a morning as it can disturb your sleep.
- Take prednisolone with or just after food as this can help protect your stomach.
- Common side effects of prednisolone include upset stomach and indigestion, swollen ankles, acne, weight gain and high blood sugars. If you are worried about any of these please do speak to your transplant team. For more information on side effects see the leaflet that comes in your prednisolone pack or speak with your transplant team.
- Never stop taking prednisolone abruptly without advice from your transplant team.
- You should be given a steroid card when you are started on prednisolone, if you were not or have lost yours please ask your transplant team or community pharmacy for a new one. Always carry this card with you and show it to anyone treating you such as another doctor or dentist.

Sirolimus

- Take sirolimus ONCE a day at the same time every day.
- The 0.5mg sirolimus tablets are not chemically the same as the 1mg and 2mg tablets. Do not take two or four 0.5mg tablets if your dose is 1mg or 2mg.
- Common side effects of sirolimus include swollen ankles hands and feet, upset stomach, mouth ulcers, acne and high cholesterol. If you are worried about either of these please do speak to your transplant team. For more information on side effects see the leaflet that comes in your prednisolone pack or speak with your transplant team.

Mood

Coping with any significant life event can be stressful and affect our mood. We all have different ways to manage stress and these may have been effective for many years but aren’t always effective in new and stressful situations. When mood suffers at these times it may be helpful to see your GP to consider prescribing options.

Alternatively, some people prefer talking therapy, and this can help to manage situations in a - way that helps to reduce the emotional impact of stress. There are some resources listed on the next page that you can consider. Alternatively, you could ask a member of the team for advice.

Useful resources

- **Getselfhelp**
  https://www.getselfhelp.co.uk/
- **Local IAPT (Improving Access to Psychological Therapies) service for Cognitive Behavioural Therapy**
- **Mind**
  https://www.mind.org.uk/
- **Mindwell**
  https://www.mindwell-leeds.org.uk/
- **Moodjuice**
  http://www.moodjuice.scot.nhs.uk/
- **Northumbria Self Help Leaflets**
  https://web.ntw.nhs.uk/selfhelp/
  https://www.nhs.uk/conditions/stress-anxiety-depression/
- Speak to a member of the hepatology team.
- Speak to your GP for referral to local resources.

Donor letter

Some people may wish to write a letter to the donor family, and we know that bereaved relatives often find it a comfort to receive them. It is possible to know some information about the person who donated their liver. Due to patient confidentiality this information is limited to the age and sex of the donor. Likewise, if a family of the donor asked for information about you, they will only be informed of your age and sex. The Liver Transplant co-ordinators can support you and your family when writing to the donor family and provide examples of the letters others have written. Occasionally the donor's family may write back to you and if this is the case, we will contact you by telephone to confirm if you would like to receive the letter.

Remote monitoring

Remote monitoring is a service used to monitor your blood results through your GP practice usually following a recent change to your immunosuppression or a variation in your liver function which may have been noticed during your previous clinic appointment. Remote monitoring is a way of safely monitoring any changes to immunosuppression and your liver function tests without you travelling to Leeds unnecessarily

The medical team will identify the bloods required and what date these should be taken.

For remote monitoring to be a success we ask you please to take responsibility in contacting your GP practice to arrange for these blood tests to be taken on or around the date identified. Once the blood results have been received back at the GP's we request that you arrange for them to be emailed to us here at Leeds for review on **leedsth-tr.postliver@nhs.net**

Support group

The St James's Liver Transplant Support Group, known affectionately as the St James's LTSG was established in **1989** with help and encouragement from the transplant team at St James's. They currently have in excess of 500 members. The group provides practical and emotional support for patients, carers, families and friends. Support can be face to face group meetings, walk and talk get togethers in various locations and via the popular private Facebook group.

Only patients of the Leeds transplant unit, their families and partners are in the group, so that members can be confident that they are sharing their experiences with people from the same hospital (St James's) with similar experiences and conditions as their own.

The group organises regular meetings both at St James's and in the North West, which often have members of staff joining us to provide updates and share information. **We would ask those interested in attending to check the website or Facebook page for up to date information.** The St James's LTSG also fundraise and are active in the promotion and awareness of organ donation which is hugely important. We also collaborate with the patient experience team and have a great relationship with many of the transplant team health professionals and engage regularly to keep up to date contact information. We also promote and are involved with National Organ Donor Awareness Week and the Transplant Games. We also provide one2one telephone calls on request and have also trialled zoom meetings. We pride ourselves on being approachable and friendly. We also engage and collaborate with charities including the British Liver Trust - they too have useful resources and website.

The closed Facebook is a safe place where members can post questions (non clinical), queries, celebrate milestones or just share friendship Thanks to our close working relationship with the hospital we can publicise updates from them quickly and share information electronically too, which mean that members can be kept updated with clear guidance promptly. We are also keen to remind members that specific advice on anything clinical cannot be provided by the group and signpost them to the relevant medical professional.

Patients can also be occasionally linked a transplant buddy on request. Please ask a member of the transplant team to facilitate this for you with one of the support group admin volunteers.

Having a transplant journey can be overwhelming at times so we offer a safe place where people can connect with shared experience. We remember with gratitude the extra-ordinary gift we have been given to us by our donors’ and their families and we endeavour to promote awareness and of the benefits of organ donation wherever and whenever the opportunity arises. If you would like more information please take a look at our website: **www.stjamesltsg.org**

We encourage you join the Facebook group (all posts private & confidential) please contact our **www.stjamesltsg.org**

Thankyou for reading this information and please do not hesitate to contact us where a warm welcome & listening ear awaits.

St.James Liver Transplant Support Group
www.stjamesltsg.org
TWO LIVES INTERTWINED BY A MIRACLE

Contact us

- **Post-transplant Clinical Nurse Specialist**
  Telephone number: **0113 206 8184** (Answer phone available during office hours for non-emergency issues)
  Email: **leedsth-tr.postliver@nhs.net**
- **Liver Unit (J83)**
  Telephone number: **0113 206 9183**
- **Pharmacy**
  Telephone number: **0113 206 6826**
  Monday to Friday (9am - 5pm)
  Email: **leedsth-tr.mmpsliverteam@nhs.net**
- **Dietitian**
  Telephone number: **0113 206 5187**
  Monday to Friday (8am - 4pm)
- **Substance Misuse Nurse Specialist**
  Telephone number: **0113 206 6315**
  Monday to Friday (9am - 5pm)

My gift has been truly life changing. I was a positive person anyway but now have a new found joy in every day, good or bad. Just so grateful to be here’

‘I am celebrating 20 years having a liver transplant this year and every year has given me something wonderful including the chance to become a mum to the most incredible little girl. I will forever be grateful to my donors’

‘My transplant was sudden andcame with a great deal of loss. I am now a proud mother to two post-transplant, have graduated, become a transplant athlete and married the love of my life. My donor a mother herself gave me a second chance and I will never take that for granted’

‘I think about and thank my caring selfless donors every day. Their extraordinary gift has allowed me to live an ordinary life and make the most precious memories with family and friends. I will be celebrating 33 years post-transplant in September with gratitude and reflection’

Questions / Notes

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