Prepared by Ms Aoife Coffey and the Transplant Team at the Liver Unit, St Vincent’s University Hospital, Elm Park, Dublin 4, on behalf of the Consultative Council on Hepatitis C, supported by the Department of Health and Children.

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A Guide to Liver Transplantation
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**Introduction**

This booklet is for people who have Hepatitis C and who may need a liver transplant at some time in the future. Each year a small number of people who have Hepatitis C develop liver problems so severe that a liver transplant may be necessary. This is either as a result of serious damage to the liver caused by the Hepatitis C virus (cirrhosis) or because of the development of liver cancer (hepatocellular carcinoma).

**What is Liver Disease?**

The Hepatitis C virus causes inflammation of the liver and for some people this leads to scarring of the liver (fibrosis) and in more severe cases to cirrhosis which is where the scarring becomes widespread throughout the liver and small lumps (nodules) develop.

A liver that has developed cirrhosis does not work as well as a normal liver and cannot carry out some of its normal functions. The individual may develop symptoms of liver disease such as jaundice, fatigue, reversal of sleep pattern, loss of appetite and weight loss, bleeding and bruising, build up of fluid in the abdomen and legs and confusion (encephalopathy). If you have some or all of these symptoms it does not necessarily mean that you require a liver transplant, however, in a small number of people with Hepatitis C liver transplant may be considered as a treatment option.

**What can I do to keep my liver healthy?**

There are several things that you can do to make sure that you stay as healthy as possible. It is important that you get rest, sleep and exercise appropriate to your needs and that you eat a healthy diet.

Protecting your liver from other illnesses is also important so it is advisable to get yourself vaccinated against Hepatitis A and B to protect your liver from further damage by these viruses.

Research has identified two specific areas that can influence the progression of liver disease in those infected with Hepatitis C. The first relates to alcohol
consumption and the second to obesity, both of which are reported to accelerate the rate of progression of liver disease and progression to cirrhosis.

The advice from the National Liver Transplant Unit is that the safest option is to avoid drinking alcohol altogether. If you find this difficult a drink on a special occasion such as a wedding or anniversary may be permitted, but for those who find they can't stop after one or two, it is better to avoid alcohol altogether. The virus is attacking your liver, alcohol is another attack. It is difficult for your liver to withstand these attacking elements.

Evidence has also demonstrated that, in those infected with Hepatitis C, being obese or overweight accelerates the activity and progression of chronic hepatitis. Weight reduction and exercise has clearly demonstrated improvement in liver function and quality of life.

**How would I be referred for transplant?**

St. Vincent’s University Hospital ensures equity of access to all our transplant services. A Consultant Hepatologist will see all referrals. If your General Practitioner or medical team believe that liver transplantation may be a treatment option for you, you would be referred to the Liver Team at St. Vincent's University Hospital. St. Vincent's University Hospital, Dublin is the Irish National Liver Transplant Centre. The team consists of Consultant Hepatologists, Surgeons and Anaesthetists specialised in Liver Transplant, Transplant Co-ordinators, Dietician, Physiotherapist, Medical Social Worker, Dentist and nursing staff.

Initially you would meet the Consultant Hepatologist in the Out-patient Department for a brief evaluation and if they feel that a liver transplant may be an appropriate treatment for you, you would then be admitted to the St. Vincent’s Healthcare Group for assessment for Liver Transplantation.

**What if I have Haemophilia or another bleeding disorder?**

St. Vincent’s medical team will work with the National Haemophilia Centre at St James’s Hospital, Dublin to ensure the best care for your bleeding disorder and the care of your liver.
What if I am co-infected with HIV?

To ensure that you get the most specialised care available, you will be referred to King’s College Hospital in London for the liver transplant itself. The initial assessment will take place either in St. Vincent’s or St. James’s Hospital. All of the Consultants from the hospitals will work together as to a team to co-ordinate your care. St. Vincent’s will co-ordinate all your transplant arrangements. Follow-up care post transplant will be done at St. Vincent’s.

What happens if I also need a kidney transplant?

A small number of patients with Hepatitis C may have kidney damage as well as liver damage. In those who also require a kidney transplant, this may be performed at the same time as their liver transplant but would be carried out by the Renal Transplant Team from Beaumont Hospital at St. Vincent’s University Hospital. Patients would attend Beaumont for their renal follow-up.

What is “the assessment period”?

The assessment period is carried out as an in-patient and takes a week to ten days. This is vitally important as it allows the team to evaluate the extent of your liver disease, and optimise all medical treatment options to ensure that you are fit enough to undergo transplant surgery and that there are no technical/surgical contraindications. It involves having a lot of tests and procedures carried out to evaluate the function of your liver, heart and kidneys. It also provides an opportunity to eliminate any potential infections and to provide advice to optimise diet and other health-related issues.

During the assessment period you will have an opportunity to meet all the members of the transplant team who will be involved in your ongoing care. You will also be provided with a lot of information about liver transplantation, its benefits and the possible complications. This will help you to make an informed choice about transplantation.
How is the decision made?

At the end of the assessment period, often after you have gone home, the team will meet and study all the results of the tests you had during the assessment period and make a decision about liver transplantation. There are several potential outcomes from this meeting -

- transplantation soon is the best treatment option and you will be placed on the waiting list now
- transplantation is indicated in the future, but not at present and you will be monitored regularly in an out-patient clinic at your own hepatology unit.
- there are other more suitable treatments for you other than transplantation at present
- transplantation would be high risk for you either due to medical or surgical complications
- for medical or technical reasons, transplantation is not always an option

You will then be either referred back to your GP or medical team, or you will be placed on the waiting list for liver transplant.

Why is a waiting list necessary?

Donated livers cannot be stored for long periods of time, usually only for a maximum of 12 hours. Livers are donated, with the consent of the next of kin, from people that are in an Intensive Care Unit, on a breathing machine and who are diagnosed as brain stem dead, usually as a result of a brain haemorrhage. When the family makes a decision to donate the transplant centres are then contacted and a suitable recipient is selected from the waiting list. To match a donor and a suitable recipient for liver transplantation, the only requirements are that they be of approximately the same size and of compatible blood groups. The waiting time is on average six to nine months.

What happens while I’m on the waiting list?

Most patients on the transplant list wait at home. While you are on the waiting list you may not leave the country but you can travel within Ireland as long as the co-ordinators are informed where you are and how long it
would take you travel to Dublin. You will be reviewed regularly at the outpatient transplant clinic and should keep the Transplant Team informed of any changes in your condition in between your clinic visits, i.e. if you are on medication/antibiotics for any reason.

When you are placed on the transplant waiting list the co-ordinator will record your contact numbers and mobile numbers. It is impossible to say when you may receive a call regarding a transplant but most commonly this occurs in the evening time.

**The Transplant Operation**

**Will the transplant always go ahead?**

In certain situations your operation may be cancelled after you have been called to the hospital. This is termed a 'false alarm'. If the donor liver is found to be unsuitable the transplant surgery will be cancelled. If this should happen you will return home and you will remain on the waiting list. This will not affect your opportunity to be transplanted in any way.

**What happens when I receive 'The' call?**

You will be contacted by the Liver Transplant Co-ordinator who will tell you when to come into the hospital and help you with any travel arrangements. They will also give you advice about fasting and where to go when you arrive at St. Vincent’s University Hospital.

When you arrive, you will need to have some further tests carried out including an E.C.G., Chest x-ray and some blood tests. You will be examined by the Transplant Medical Registrar and will be asked to sign a Consent Form for your surgery and anaesthetic. Your family will be able to stay with you until you go to theatre.

**What happens when I get to theatre?**

You will be transferred from your bed to the operating table. You will be attached to a monitor to observe your heart rate, a blood pressure cuff will be placed on your arm and a probe will be placed on your finger. An
intravenous cannula (drip) will be put into a vein on your hand and you will then be given drugs to send you to sleep.

When you are asleep a tube will be placed in your lungs to do your breathing for you and a number of other tubes and drips will be placed in your nose, bladder, neck and arms to monitor you very closely throughout the transplant operation. This generally takes about an hour to complete.

Once this has been completed the surgery will begin.

In order to do a liver transplant it is necessary to first remove the damaged liver and then to attach the new liver to your blood vessels. These procedures take, on average, approximately four to six hours. The gallbladder is also removed at the time of the surgery to prevent the development of gallstones or infection at a later stage. Some recipients may find that they cannot tolerate a very fatty diet as well, as they used to, but in reality most find it does not influence their eating habits.

When the surgery is finished you will be returned to an Intensive Care bed and will remain on a ventilator (breathing machine) for the rest of the day to allow you time to recover from the surgery.

Over the next few days you will be encouraged to get out of bed, take short walks, start eating and look after yourself as much as possible. Gradually all the tubes and drips will be removed and you will start to learn about your immunosuppression (anti-rejection) medications.

**Recovery**

**How long will it take to recover?**

This depends on how ill you were before your surgery and also on the complications you may develop following your surgery. Most patients spend a few days in Intensive Care and two to three weeks in hospital. Some recipients chose to avail of a short period of convalescence before going home.
What are the possible complications of liver transplantation?

During the surgery there are risks associated with bleeding problems as well as the technical difficulty of removing the damaged liver and implanting the new liver. Immediately after the operation bleeding, poor or non-function of the new liver, blockage of the blood supply, infection and rejection are all possible risks that are monitored.

In the longer term, narrowing of the blood vessels and ducts can occur as well as side-effects of the anti-rejection medication. The new liver will be infected by Hepatitis C although serious symptoms may take years to occur.

All of the potential complications will be discussed with you, in detail, prior to your being placed on a waiting list for transplantation.

How long will I have to take the anti-rejection medications for?

You will need to take the anti-rejection medication for the rest of your life. As your body adjusts to the new liver the amount of medication you need to take may be reduced. There is a programme for teaching you about your medications while you are in hospital recovering from your transplant so that by the time you are going home you are familiar with the medications that you are taking and any special requirements.

People who take anti-rejection medication may be more susceptible to other infections so it is important that you take more care to avoid exposure to infection. Any illness should be reported to your doctors.

You must check with the transplant team before taking medications bought without a prescription in your local pharmacy and any herbal or homeopathic remedies as these may interact with your anti-rejection medications.

How often will I have to attend the Transplant Clinic?

After you leave the hospital following the transplant operation you will be reviewed at the transplant clinic every week/fortnight. The intervals between your clinic visits will be gradually increased and recipients who are two years
post transplant, with no complications, generally attend every six months. Follow-up is for life to allow for monitoring for complications of the anti-rejection medication as well as recurrence of disease.

**When can I go back to work/college/school?**

When you return to work depends on the type of work you do, whether it is very physical or not and your general recovery. In those recipients whose jobs are very physical and require heavy lifting, returning to work may take longer in order to provide sufficient time for your wound to heal fully. Most recipients can return to work within three to six months. We would suggest that, if it were possible, you return to work on a part time basis initially, and gradually increase your hours.

**Are there any restrictions following my transplant?**

The aim of transplantation is to return the individual to a normal lifestyle or as near normal as possible. In the initial three to six months following your transplant you will experience some physical limitations in relation to certain activities, such as lifting or sporting activities. Returning to these activities should be on a gradual basis.

You are advised not to drive for a minimum of eight weeks following your transplant and to discuss this with the transplant team. This is because your reaction time may be slower and you may experience some temporary blurring of your vision as your body adjusts to the anti-rejection medication.

You are also not advised to travel outside Ireland in the first few months after your transplant. When you do travel it is important to ensure you are travelling to an area where the hygiene is good and that you bring a letter of information with you, provided by the transplant co-ordinators. All vaccines should be confirmed with the Liver Team, as there may be types of vaccines you should not receive or that may not be as effective because of your anti-rejection medication.
When can I resume sexual relations?

Feelings of unattractiveness, the stress of the operation and your hospital stay may cause difficulties in resuming close physical contact with your partner. This is natural and normally resolves with time. It is important to keep your lines of communication open. Sexual activities may be resumed as soon as you feel ready. If you have lost your sexual drive, which is very common in patients with liver disease prior to transplant, talk it over with the members of the transplant team.

A Final Word

Liver Transplantation is a very successful procedure but like any major operation carries risks and complications as well as a lifetime of anti rejection medication. When and if you are selected for the waiting list it will be because the transplant team is convinced that the procedure is your best option to prolong and improve your quality of life. Most people who undergo liver transplantation return to a normal life once they take sensible precautions and look after their general state of health.

The liver team are there to support you and your family and monitor your condition throughout the transplant process.

Should you have any further questions or require further information, please contact the Liver Transplant Co-ordinators at:

The Liver Unit,  
St. Vincent's University Hospital, 
Elm Park, 
Dublin 4.  
Tel: 01-2094131 / 01-2695573  
E-mail: liver.transplant@st-vincents.ie
USEFUL ADDRESSES
1. Support groups

**Positive Action**
56, Fitzwilliam Square
Dublin 2.
Tel:  (01) 676 2853
Fax: (01) 662 0009
E-mail: posact@indigo.ie
Positive Action provides information and support to women who have Hepatitis C from infected Anti-D products administered in Ireland, and to their families.

**Transfusion Positive**
3 Clanwilliam Square
Dublin 2
Tel:  (01) 639 8854 / 55
Fax: (01) 639 8856
E-mail: transfusionpositive@eircom.net
Transfusion Positive provides information and support to people who have Hepatitis C from a blood transfusion in Ireland, and to their families.

**Irish Haemophilia Society**
Block C
Iceland House
Arran Court
Arran Quay,
Dublin 7.
Tel:  (01) 872 4466
Fax. (01) 872 4494
E-mail: haemophiliasociety@eircom.net
Website: www.haemophilia-society.ie
The Irish Haemophilia society provides information and support and services to all people with bleeding disorders who have Hepatitis C, and to their families.
The Irish Kidney Association provides information and support to people with kidney problems, including people who have Hepatitis C through dialysis or organ transplant, and to their families.
USEFUL ADDRESSES

2. Specialist Centres

St. Vincent’s University Hospital
Liver Unit,
Elm Park,
Dublin 4
Tel: (01) 209 4131 / (01) 269 5573
Fax: (01) 283 7724
E-mail: liver.transplant@st-vincents.ie
Website: www.st-vincents.ie

Beaumont Hospital
Hepatology Unit,
Beaumont Road,
Dublin 9.
Tel: (01) 809 2220 / (01) 809 3000
Fax: (01) 809 2219
Website: www.beaumont.ie

Mater Misericordiae Hospital
Hepatology Unit,
Eccles Street,
Dublin 7.
Tel: (01) 803 2048 / (01) 803 2000
Fax: (01) 803 4058
Website: www.mater.ie

St. James’s Hospital
Hepatology Unit,
James’s Street,
Dublin 8.
Tel: (01) 410 3417 / (01) 410 3000
Fax: (01) 410 3418
Website: www.stjames.ie

Our Lady’s Hospital for Sick Children
Hepatology Unit,
Crumlin,
Dublin 12.
Tel: (01) 409 6742 / (01) 409 6100
Fax: (01) 456 3033
Website: www.olhsc.ie

Cork University Hospital
Hepatology Unit,
Wilton,
Cork.
Tel: (021) 492 2274 / (021) 454 6400
Fax: (021) 493 6383

University College Hospital
Hepatology Unit,
Galway.
Tel: (091) 544370 / (091) 524222
Fax: (091) 520233
Website: www.grh.ie/uchg.htm

St. Luke’s Hospital
Hepatology Unit,
Kilkenny.
Tel: (056) 7785329 / 7752310 / 7785000
Fax: (056) 7752232
USEFUL ADDRESSES
3. Other Addresses

**Hepcats**
Tel: 087 791 7742
E-mail: hepcats_dublin@hotmail.com
Hepcats is a self-help group set up by and for people living with Hepatitis C.

If you have a problem with drugs contact:

**Merchant’s Quay Project**
Merchant’s Quay
Dublin 2
Tel: (01) 679 0044
Fax: (01) 671 3738

**Drug Treatment Centre Board**
Drug Addiction Treatment Centre
Trinity Court
30 Pearse Street
Dublin 2
Tel: (01) 6488600