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An Introduction to Liver Transplant Assessment

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An introduction to liver transplant assessment

These notes will help you to understand the process of liver transplant assessment and how it will affect you and your family.

There are two forms of assessment; some patients will be admitted to the hospital for a period of around five days, others will undergo assessment as an outpatient, attending the hospital on two separate occasions. The letter which accompanies this booklet will explain whether you are being assessed as an inpatient or as an outpatient and give specific information about dates, times and so on.

It is important to stress that undergoing an assessment does not commit you to having a transplant. At this stage it is about making sure that a liver transplant is the right operation for you, and about giving you as much information as we can so that you can properly understand what is involved.

It is also your opportunity to ask any questions you may have. It is strongly recommended that you write these questions down, so when you come to the assessment you will not forget to ask. Some people find it helpful to keep a note-book for this. If these questions need to be answered before you come for the assessment please feel free to contact us, we will be happy to talk things through with you. Telephone numbers are given at the end of this leaflet.

If your assessment is as an inpatient you need to check that your hospital bed is available. Please check before you leave home on the day of your admission, as outlined in the admissions letter.

Liver transplantation

One of the main purposes of the assessment is to explain to you what liver transplantation involves. The vast majority of people do extremely well after a liver transplant; however, it is important for you understand that it is a very big operation and not everyone will survive. You need to understand not only the benefits of transplantation but also the risks and potential

complications. Hopefully, the better informed you are the less frightening the experience will be.

Indications for transplantation

Most people who undergo liver transplant have a chronic liver disease which is limiting their life expectancy. Without a transplant they may only have a few years to live. Other patients have a very poor quality of life due to the symptoms of liver disease. For them the aim of the transplant is to restore their health and improve their quality of life. In this situation, liver transplant is offered only if all other forms of treatment have failed.

Life after transplantation

Life after transplantation for the vast majority of people is usually extremely good, but it can never be considered as completely normal. Regular check-ups and daily medication is vital. The aim of the transplant is to restore you to a level of fitness to allow you to live a full and active life.

You have to consider a transplant as a swap; you are swapping one liver (which is making your life intolerable or greatly limiting the length of your life) for another liver that will enable you to return to a near-normal quality of life.

You will need to attend for follow-up after transplantation. Initially, this will be in here in Birmingham where we will need to see you every one to two weeks for the first three months. For some people this will involve a lot of travelling which we appreciate can be very tiring at first, however, we cannot stress enough how important this early follow-up is. As you get stronger, your follow-up attendances will be less frequent and you may be asked to attend appointments in Birmingham only once or twice a year. We try to share follow-up appointments with the local hospital and family doctor. We are aware there are financial implications for many people. Depending on your circumstances

you may be entitled to reclaim your travelling expenses.

You will need to take anti-rejection drugs for the rest of your life. These drugs prevent your body's immune system from damaging the liver – a process known as 'rejection'. The drugs can have a number of side effects and you will be monitored carefully for these. The dose of these drugs needs to be carefully monitored; too much anti-rejection medication can be just as harmful as too little, so treatment is tailored to the individual.

When considering transplantation therefore, it is important for you remember you will need lifelong follow-up appointments at the Queen Elizabeth Hospital Birmingham.

Transplantation is rarely a cure

In some cases, the original disease will come back and affect the new liver. However, this depends mainly on the reason for the liver disease. There are usually treatments that can be given either to prevent recurrent disease or to reduce any damage to the liver. Recurrence usually does not cause major problems but it is something you need to be aware of.

What happens in the assessment?

The purpose of the assessment is to ensure that a liver transplant is the right operation for you, at the right time, and to make it as safe as possible. The doctors, surgeons and anaesthetists need to know you are strong enough and fit enough to undergo the procedure. It also gives you the opportunity to find out what the transplant involves and to familiarise yourself with the hospital and meet some of the staff.

We will take a medical history from you. A liver transplant is a very big procedure with its own risks and dangers. In order to minimise these risks we need to know if you have any other medical problems, if we know about them in advance we can prepare for them and find ways around them.

You will have a number of test and investigations during the assessment and meet various members of the liver team, including a surgeon, anaesthetist and hepatologist.

Transplant coordinators are specialist nurses who coordinate the assessment process and organise your admission to hospital at the time of the transplant. They will meet you at the start of your assessment, explain what will happen and give you a booklet which explains all about the assessment and the process of having a liver transplant. They also talk to all of the patients (and their carers) in depth about the transplant process.

Our experience has taught us how important it is that patients have support from family/friends (carers) through the transplant process. Your main support person (carer) will be expected to attend on at least one day of the assessment so that they too can fully understand the process of transplantation – this will help them to better support you, the patient. We do not add a patient's name to the transplant waiting list until we have met with their nominated carer and have a clear plan for support following the transplant.

Depending on the cause of your liver disease, you may meet an addiction / psychiatry nurse as part of your assessment.

The Patient Support Group also visits and talk about their experience of having a liver transplant. People undergoing assessment often tell us how valuable it was to meet the Support Group and talk to a person who has already been through the transplant process.

Tests and investigations

Almost every patient will have an ultra sounds scan of their abdomen, a chest X-ray, a 12 lead ECG, an echocardiogram and a number of blood tests during their assessment. Depending on the cause of your liver disease and your general health, you may also have other tests such as a CT or MRI scan or lung function tests. Some patients may have had some of these tests at their local

hospital before the assessment, but it may be necessary to repeat them here. The transplant coordinators and doctors will talk to you individually about the tests you need.

How long will it take?

Patients undergoing inpatient assessment usually stay in hospital for four or five days, though for some people the stay may need to be longer and you could be in hospital for several weeks.

Outpatient assessments require two visits to Birmingham, one for a day when all of the investigations and blood tests will be done and a second visit for two days requiring an overnight stay if you live a distance away from Birmingham. Your assessment letter will explain this arrangement and give details about accommodation in more detail.

Sometimes the assessment will lead us to ask for further tests and investigations, perhaps on your heart or lungs for example. These may be organised here in Birmingham or at your local hospital depending on your circumstances. Sometimes this process can cause a delay before you actually complete the assessment or are added to the transplant waiting list.

Family involvement

Recovery from a liver transplant can sometimes be a slow and difficult process and the transplant is not always successful. In this situation family members are likely to have difficulties coping with their worries about the patient, especially as they are likely to be a long way from home and may feel lonely and unsupported. One of the aims of the assessment is to ensure that families (carers) are prepared for such eventualities and therefore we feel their attendance at the coordinator's teaching session is vital.

Whether you wish members of your family to stay with you for the whole of the assessment is entirely a matter for you and them to decide. Although it is often helpful to have relatives to

support you, we understand that due to other commitments it is not always possible or desirable for support to be there all the time. Details of the accommodation available are included in your admission letter

Outcome

At the end of your assessment, we (you and the transplant team) will come to one of several conclusions:

- 1) You may be put on the transplant list and then wait for a liver to become available.
- 2) You may decide transplantation is not for you.
- 3) We may advise that liver transplantation is not appropriate at this time and that other treatments may be safer or more effective.
- 4) There may be times when we cannot offer transplantation. We may feel that transplantation is not technically possible, or that for other reasons you are not a suitable candidate for liver transplant. This can be very upsetting and disappointing. It is important that you understand the reasons for our decision; your Consultant will be happy to talk things through with you and your family. We can refer you to another transplant centre for a second opinion if you wish.
- 5) You may wish to go home to think through your options before you make up your mind.

Finally...

Liver transplantation is a very difficult time for you and your family. We do appreciate this and will do our best to help you through it. Detailed information is often helpful in understanding the issues involved. Therefore, please remember to ask if there is anything you wish to know or if any aspect is unclear.

One of the difficult things about liver transplant is waiting for a suitable donor. It is impossible to predict how long a person will wait

for their transplant. It is important also to be aware that following a transplant, whilst many people will recover quite quickly, the recovery period can sometimes be slow and difficult. It may be 6 to 12 months before you feel you have made a full recovery.

You can find further information about liver transplant at the Queen Elizabeth Hospital Birmingham on our website:
www.uhb.nhs.uk/liver-unit.htm

Contact numbers

If you want to speak to your Consultant's secretary ask the switchboard to put you through to them:

Queen Elizabeth Hospital Birmingham
Switchboard: 0121 627 2000

For inpatient assessment enquiries:
Waiting list Co-ordinator: 0121 371 4978

For outpatient assessment enquiries:
Liver Transplant Co-ordinators: 0121 371 4529

Accommodation Office: 0121 371 4524

Disclaimer

This information booklet is to be used in conjunction with discussions and education by the staff on the Liver Unit. Although fairly comprehensive, the information given may alter due to protocol amendments and more importantly, because of the individuality of your care.



The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm

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