

Scottish Liver Transplant Unit Social Work Service

Information for Patients

Social Work (SLTU)
Royal Infirmary of Edinburgh
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You can get this document on tape, in Braille, large print and various computer formats if you ask us.

Please contact:

**Interpretation and Translation Service (ITS) on
0131 242 8181 and quote reference number 11385.**

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Introduction

Many patients who are admitted to the Scottish Liver Transplant Unit (SLTU) at the Royal Infirmary of Edinburgh (RIE) for liver transplant assessment are travelling from areas outwith Edinburgh. This can cause many practical problems for families and can increase their stress at a time when they need all their energies to focus on the assessment week.

The aim of this leaflet is to provide you with practical information to help with some of these problems. The leaflet is sent before your admission, so you have time to read it at home and act on any of the information that may be appropriate for you.

This leaflet also informs you about the role of social work within the unit. Most patients will be assessed by the social worker during their assessment week. This booklet informs you about their role. Some patients may have already had contact with social workers in their own community due to problems associated with their liver disease, or for other reasons. However, for many this will be the first time that they have contact with a social worker.

What we do

The SLTU social work service provides a pre-transplant assessment of your social circumstances.

The social worker is an integral member of the liver transplant team. We are hospital-based and attend:

- ward rounds
- the meeting where liver transplant listing decisions are made (the assessment meeting)
- out patient clinics.

The social worker is just one of many professionals who may see you in the assessment week. Our involvement is to provide the transplant team with an overview of your home life; assessing your strengths and identifying areas where you might need more support.

The uncertainty, the waiting and actually undergoing a liver transplant can be a stressful process, which can impact on all areas of your life. This is why we assess and provide support in areas such as:

- Housing
- Employment and education
- Finances and benefits
- Mental health, advocacy and therapeutic interventions
- Addictions
- Family and social networks
- Childcare
- Safeguarding
- Carers support

Waiting list support

If you are listed for liver transplant, we will let you know of the support services that are available.

We can also help link you into local support networks. Every family is different; some will use our services a great deal, but for others they may choose to cope in a different way.

There is also a support group facilitated by unit social worker that is held on a six weekly basis... Times and dates of this group available on request.

Support after your transplant

If the medical team feel that you need support at home to ensure a safe discharge, they will let us know and we will visit you on the ward. Some patients may need a home help or basic equipment, such as rails, on discharge.

We may also review your situation in clinic. If all is well, we will close your social work case files. However, you can still make contact with us after this point.

How to get in touch or make a referral

There are several ways you can contact us either for yourself or to refer someone else.

Phone:

0131 242 7850

Bleep:

Ask a member of staff in the ward or the outpatient clinic to page us.

Write:

Social Work (SLTU)
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh
EH16 4SA.

Visit:

Visit the office to make an appointment.

The social work office is located on the ground floor of the RIE (opposite the Sanctuary).

If at clinic then you can ask the receptionist to call social worker for transplant unit.

EMAIL; Fiona.dawson@edinburgh.gov.uk
Aisling.downey@edinburgh.gov.uk

Financial and benefits information

Living with a liver disease and having a liver transplant can be an extra financial burden for both you and your family. There are costs involved in accommodation for relatives, travelling to clinics and 'living' in the hospital. For example, hospital car parking can cost up to £10 a day (Park and Ride is a much cheaper option), and there are charges for using the TVs etc.

Many people have had to give up work because of ill health or because they care for a relative. It is therefore important to check what benefits you and your carer or family might be entitled to.

Types of benefit

You can discuss your situation with the social worker when you are in for assessment or you can find this information before you are admitted.

Common benefits claimed include:

- Employment and Support Allowance
- Statutory Sick Pay
- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- Attendance Allowance.
- Carers Allowance
- Disability Premiums.

Some benefits can be affected by your hospital admission. For more details on this and on a full range of benefits, please visit www.direct.gov.uk which has an online Benefits Checker.

There is also a CAB worker who works part time in the hospital and and they can come and see you in the ward if you have benefit queries.

Please note that many benefits will significantly change due to the Welfare Reform Act 2012.

Please see www.dwp.gov.uk for updated information.

Citizens Advice also provides telephone, online and face-to-face assistance. However, certain offices can be particularly busy and it might be wise to ring first. Contact details can be found in the local phonebook or online at www.cas.org.uk

Some other organisations also provide benefit advice such as:

- Macmillan
- Local Carer Support Organisations.
- Some large GP practices and Housing Associations.
- Local councils/welfare benefits team.
- Citizens Advice Bureau (CAB)

Grants and financial help

If you and your family are experiencing financial difficulties, some voluntary organisations offer small grants to help in certain circumstances. Also, if you are on certain benefits, you may be able to access the Scottish Welfare Fund. Please contact your local council for further information.

In cases of extreme financial difficulty, please speak to the social worker in the unit, who may be able to help you identify if there are any other sources of support.

Transport and travel information

Hospital transport is only available to patients if they are assessed as medically requiring this service. Eligible patients must phone the Central Ambulance Control themselves on 0300 123 1236.

If you are assessed as not meeting the medical criteria and none of your family and friends can bring you to hospital, you will have to make and pay for your own travel arrangements, which you may be able to claim back afterwards. (See pages 12 to 15.)

Reimbursement of travel expenses

If you are on a means-tested benefit, you may be able to get some financial help to cover your travel costs when using public transport, your own car (not taxi) or by air in some circumstances.

Means-tested benefit includes:

- Income Support
- Job Seekers Allowance (JSA) (income based)
- Working Families Tax Credit
- Child Tax Credit
- Disabled Persons Tax Credit
- Employment and Support Allowance (ESA)
(income based)
- Pension Credit (Guarantee Credit)
- War Pension

You may also be able to get help if you have:

- An HC2 (Help with health costs certificate)
- An HC3 (Help with health costs certificate)
- Tax Credit Exemption Certificate

You can apply for an HC2 or HC3 if you are on:

- PIP
- Contributory ESA
- Contributory JSA
- Working on a low income

If you qualify for help in any of the ways listed, then you should take the following to the Royal Infirmary cashier's office, located near the main entrance:

1. Travel receipts or tickets for public transport. If you come by car you will be given a standard mileage rate for petrol (18p a mile) so there is no need to give us fuel receipts.
2. Patient's Travelling Expenses Certificate of Attendance. Nursing staff in OPD1 or Ward 206 will give you this if you ask.
3. Written proof of your benefit claim, **no older than four weeks for ESA and JSA, and three months for the all others.**
4. HC2/3 form if you have one.

If you are in receipt of an appropriate benefit but cannot produce proof of this then you should be given an HC5 by the cashier to complete. This will then be forwarded to your local Department of Work and Pensions.

Travelling from other health boards

There are fourteen regions in NHS Scotland, and each has its own policy in relation to reimbursing patients who do not receive a qualifying benefit:

Ayrshire and Arran Patient Travel

All patients can claim for travel with transport receipts. If travelling by car, you will be reimbursed at 14p a mile.

Patients can claim for up to £50 per room, per night where an overnight stay is required. If claiming for an escort, your GP or consultant must have confirmed in advance that an escort is required.

You should then complete an Ayrshire and Arran claim form and send to:
Out of Area Expenses Travel Claims, Finance Department, Stair Team Base,
Ailsa Hospital, Dalmellington Road, Ayr, KA6 6AB.

Highlands and Islands Patient Travel

If a patient has to travel more than 30 miles to attend hospital, they are entitled to reclaim travel and necessary B&B expenses less a statutory deduction of £10. Mileage is reimbursed at 14p a mile and accommodation at up to £36 per person, per night.

Submit a signed NHS Lothian travel expenses claim form with receipts to:
NHS Highlands and Islands Finance Department, Beechwood Park,
Inverness, IV2 3BW. Telephone 01463 704 874.

Greater Glasgow and Clyde Patient Travel

This has been devolved to individual hospitals; there is no single policy for the area. Contact your consultant's secretary for further information.

Alternatively call the finance department at NHS Greater Glasgow and Clyde on 0141 414 6101. Speak to referring hospital re transport/travel costs.

Dumfries and Galloway Patient Travel

Submit a letter to the Director of Finance stating your individual case for reimbursement to:

NHS Dumfries and Galloway, High East Crichton Hall, Bankend Road
Dumfries, DG1 4TG.

Borders Patient Travel

Patient's mileage is reimbursed at 16.5p a mile. Keep your receipts for public transport and accommodation, and write to:

Administration Department, Borders General Hospital, Melrose TD6 9BS. TC
01896826045

Western Isles Patient Travel

Before travelling, go to your local Patient Travel Office (Lewis and Harris, Benbecula and Uists, or Barra) and get a claim form. Have this signed by a hospital staff member during your stay in Edinburgh. Your expenses can then be reclaimed at your local office when you return.

Patients can claim up to £50 accommodation per person, per night. If claiming for an escort, you can £70 per night accommodation but will need evidence from referring consultant. Mileage is reimbursed at 24p per mile if using own car.

See www.patienttravelwi.scot.nhs.uk or telephone: 01851 708 021.

Fife Patient Travel

Patients travelling to neighbouring Edinburgh, Lothian and Tayside are not eligible for re-imbursement from NHS Fife.

Forth Valley Patient Travel

Submit a letter to the Director of Finance stating your individual case for reimbursement to:

NHS Forth Valley, Carseview House, Castle Business Park, Stirling, FK9 4SW.

Grampian Patient Travel

Patients using their own car are reimbursed at 14p a mile. Accommodation is up to £35 per person per night, but your GP or consultant must approve any escort as medically necessary beforehand. A certificate of attendance and receipts where appropriate should be submitted to:

Audrey Beattie, Finance Manager, NHS Grampian, Westholme, Queens Road, Aberdeen, AB15 6LS.
Telephone: 01224 554 150.

Lanarkshire Patient Travel

Ask your consultant's secretary to send a letter to the finance department of Monklands Hospital with your receipts for petrol, public transport or accommodation attached.

The address is: The Finance Department, Corporation Buildings, Monklands Hospital, Monkscourt Avenue, Airdrie, ML6 0JS.

Lothian Patient Travel

Patients must be in receipt of qualifying benefit.

Orkney Patient Travel

Mileage is reimbursed at 13p a mile. Accommodation is reimbursed at up to £50 per night, per person. If claiming for an escort, your GP or consultant must have confirmed in advance that they are medically required.

On referral your consultant's office will provide a travel claim form, which you should get signed in Edinburgh. When you return, send this and relevant receipts to:

Travel Administration, NHS Orkney, Garden House, New Scapa Road,
Kirkwall, KW15 1BQ.

Telephone: 01856 888 045.

Shetland Patient Travel

If travelling more than 30 miles to attend hospital, you can reclaim transport and necessary B&B expenses less a statutory deduction of £10. Car mileage is reimbursed at 14p a mile and accommodation at up to £36 per person, per night. If claiming for an escort, this must be approved as medically necessary by your GP or consultant beforehand.

Submit your claim and receipts to:

Patient Travel, Gilbert Bain Hospital, South Road, Lerwick, ZA1 0TB.

Telephone: 01595743305

Tayside Patient Travel

Please contact your allocated social worker to progress this.

Northern Ireland Patient Travel

The referring consultant will refer to the Health and Social Care Board for funding for patient travel and accommodation.

Once approved, the Health and Social Care Board will arrange patient transport and accommodation.

Telephone: 028 9055 3711

IMPORTANT- Please note the above information may I alter slightly and if unsure please contact the NHS number of your local health board. Please

ensure you keep all receipts and letters of attendance to submit to local health boards.

Accommodation in Edinburgh

The Scottish Liver Transplant Unit has a limited supply of rooms for carers and relatives within the RIE. These cost £20 a night, and some are located in the “Doctors’ Mess”.

There is a flat available for family members to book into when their relative is undergoing assessment or treatment at the unit. If you require accommodation it is advisable to contact the unit social worker as soon as you receive the letter stating you are to come to the unit for assessment. Early contact will increase the chance of securing the flat due to high demand for this resource. For further information on this please contact the unit social worker on 0131 2427850.

Email Fiona.dawson@edinburgh.gov.uk/aisling.downey@edinburgh.gov.uk

Many patients come from different areas of Scotland and their relatives or carers often want to accompany them, but unfortunately accommodation cannot be provided for all.

Whilst we cannot recommend any hotels or bed and breakfast (B&B) accommodation, the Scottish Tourist Board (Visit Scotland) can assist with location and booking.

Some health boards reimburse some of the costs of accommodation. **You are advised to check with them before you travel.**

Scottish Tourist Board Booking line: 0845 225 5121

Book Online: www.visitscotland.com

Support services

If you are listed for liver transplant and you would like more support, there are several other services and resources available to you:

Living on the List Support Groups (held six weekly in RIE)

Social workers who can arrange to see you in clinic or link you into appropriate support networks in your area.

Liver Transplant Support Line Newsletter.

If you are listed for liver transplant, we will send you information about all of these.

Confidentiality

The Data Protection Act 1998 means that we are bound by law to keep information about you confidential. However, sometimes the law allows us to share information without your permission, e.g. to protect a child.

The law also allows you to ask for a copy of all the personal information that Health and Social Work hold about you. However, there are specific procedures to do this, which are detailed in NHS and social work leaflets.

At the time of assessment, you can ask the social worker if you can see a copy of your social work liver transplant assessment, and this will be shared with you at your clinic appointment.

Where is information stored

Although we work for the Scottish Liver Transplant Unit, we are managed by Edinburgh City Council and this means we have to record your social work case notes in their secure electronic server.

We also record some information in your medical notes and some in social work paper files. This information is also used to help us evaluate our service.

At the assessment, we will ask you if we can share certain details with other agencies who may be involved in your care. You may choose not to give consent, but please be aware that this may result in delays and difficulties in providing services to you because of lack of information.

For more detailed information on confidentiality and how to access information, there is a series of leaflets available. To request copies you can contact the NHS Helpline on 0800 224 488.

Raising concerns

If you are not happy with the care you have received from the social worker in the unit and you are unable to discuss with the worker involved, you should in the first instance make contact with the Senior Social Worker Gail James on 0131 242 7850.

Useful contacts

Liver conditions and transplant information

www.britishlivertrust.org.uk	Helpline (free) 0800 652 7330
www.pbcfoundation.org.uk	Tel. 0131 225 8586
www.transplantfoundation.org	
www.bts.org.uk	British Transplantation Society
www.transplantkids.co.uk	
www.macmillan.org.uk	Cancer support 0808 808 0000

Carer information

www.carers.org	Link into local support services for carers
www.mecopp.org.uk	Minority ethnic carer support and advice

Mental Health

www.samaritans.org Helpline 0845 790 9090	Confidential emotional support
www.breathingspacescotland.co.uk Emotional support for people who are depressed or experiencing low mood. Tel 0800 838 587	
www.crusescotland.org.uk Tel 0845 000 2227	Bereavement support

General NHS information points

Patient Information Centre (PIC) Leaflets, information and help. The PIC is based in the main mall at the Royal Infirmary.

Tel. 0131 242 7160

NHS Inform www.nhsinform.co.uk

A helpline and web-based resource for health and carer information in various languages. Tel 0800 224 488.

Feedback

We hope that this booklet is useful to you and helps you to prepare for your assessment in the liver transplant unit. Please feel free to contact us if any of this information is unclear or you feel we need to change or add anything, as phone numbers, services and benefits can change over time.

Please send your feedback to Liver Transplant Social Work at the address on page 7, or telephone 0131 242 7850.

Thank you.