

# Involving carers at the Scottish Liver Transplant Unit Edinburgh Health and Social Care Partnership

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The Scottish Liver Transplant Unit (SLTU) is a national service based at the Royal Infirmary of Edinburgh to meet the needs of people in Scotland who require a liver transplant.

In this impact story, we consider how the SLTU identify, involve and support carers.



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We believe that participation in the planning of care, the setting of realistic goals and the achievement of goals should involve the patient, their relatives, carers and all members of the multi-disciplinary team

Adam Duncan-Rusk, Service Manager



## Background

The SLTU is part of the Edinburgh Transplant Centre, which was established to support people who may require a liver, kidney or pancreas transplant. The unit consists of 20 ward beds, five high dependency unit beds and two intensive care beds.

Patients typically attend the SLTU for one week for assessment for transplant and if eligible are then placed on the transplant waiting list. Liver transplant surgery is life changing and most patients will require support before and after surgery with significant impact on unpaid carers.

Staff, volunteers and carers at the SLTU had identified key issues around lack of involvement and information being provided to carers and opportunities to improve support for carers. An established carer support service was already based in the hospital.

## Approach

In 2017 the carer support worker role at SLTU was trialled for 12 weeks with a focus on improving carer experience and involvement during the assessment week. Following the success of the trial the role has been extended and additional activity has developed based on carer needs identified. For example, this includes a peer support group and carer education sessions.

### Role of the carer support worker

- **Involvement:** following identification of carers by social work on the first assessment day their involvement is supported by ensuring they have all the information they require and understand their rights.
- **Assessment and support planning:** once a patient is added to the transplant waiting list an Adult Carer Support Plan (ACSP) is completed with the carer and all support options explored. Regular follow up and review is provided while on the waiting list and post surgery.
- **Referral to local services:** ACSPs are shared with local social work teams in the relevant local area and contact made with local carer centres where appropriate.
- **Assisting facilitation of support group:** the group offers peer support, information and education on a wide range of issues including, accessing benefits, emotional support, impact of transplant e.g. nutrition, sun protection.
- **Staff training and awareness:** discussion with staff, signposting to training, assisting with queries.

## Impact

The care support worker has held conversations with carers and staff to understand the impact of their work.

### Impact for carers

- Carers **feel they have more right to be in the room** and to have their view heard throughout their loved one's involvement with the SLTU.
- Carers **feel more involved and supported** as there is time to focus on their needs.
- Being able to speak to someone who has a carer focus **enables the carer to speak about their challenges** and has provided essential support to maintain and improve relationships.

### Impact for staff

- Less information needs to be repeated during appointments as **carers are more prepared and informed.**
- Early involvement of carers has led to **less appointments being duplicated.**
- **Carer issues can be identified and resolved** early through support from the carer support worker.
- **Increased referrals to local carer organisations** across Scotland.



## Key enablers

- **Approach to carer identification**  
Conversations to identify carers have been successful as discussions focus on describing the caring role and recognise that many family members will not identify themselves as a 'carer'. Patients are asked 'who will help you at home once you are discharged from hospital?'
- **Relationships with social work**  
Supporting carers on a national scale from an Edinburgh hospital can be challenging as each council area and support team operate differently. Developing relationships with social work departments across Scotland has helped to ensure smooth access to local carer support.
- **Development of carer support based on needs identified**  
Support has developed based on needs identified so has been led by carers e.g. peer support group now involves British Liver Trust, SLTU staff and social workers and the content of sessions is based on what carers want to know.

## Opportunities for improvement

- **Resources for carer education**  
It can be challenging for carers to have the level of understanding needed to be fully involved in care planning due to the complexities of the system. It would be helpful to have additional resource for carer education.
- **Inclusion of carer plan as part of assessment**  
To further demonstrate and recognise the value of carers, the Adult Carer Support Plan could become a formal part of the unit assessment via a dedicated Carer Support Worker.

## Further information

Find out more about the work of the SLTU on their [webpages](#).

The Unpaid Carers Improvement Programme is part of Healthcare Improvement Scotland's Improvement Hub (ihub). Visit our webpages to read more about our improvement work, including further impact stories, on our [webpages](#).