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Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Specialised Services Policy:

CP30 Live Donor Expenses

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Document History

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Policy Statement

<p>Background</p>	<p>Transplantation is cost effective and clinically preferable, where appropriate, to other Renal Replacement Therapies. Members of the public, who donate a kidney, whilst alive, incur expenses and/or incur costs.</p>
<p>Summary of Access Criteria</p>	<p>To encourage donations in general and ensure that donors do not suffer financial hardship, Kidney donors to Welsh patients will be compensated for their reasonable expenses and loss of income at the time of making the donation.</p> <p>Any payment to living donors should ensure that, within reason, the donor is no worse off as a result of the donation, but neither should they gain any financial advantage. Any payment in excess of the amount needed to reimburse losses would constitute a payment for the donation and breach the HOT Act 1989.</p> <p>Loss of Earnings</p> <p>The level of reimbursement will depend on any other sources of reimbursement available to the donor. Typical absence from work is usually up to 12 weeks and this may involve entitlement to full / reduced / basic / no pay.</p> <p>The following positions are confirmed for each of the different categories of employment.</p> <p>Employed Donors</p> <p>Some employers may fully support the donor and will pay full salary to the employee throughout their absence from work. Other donors may receive full pay initially from their employers, but after a few weeks may only receive statutory sick pay. In addition, there is a third group of donors who may only receive Statutory Sick Pay from the start of their absence from work. Reimbursement is to be calculated from of the difference between the validated claim and Statutory Sick Pay up to the</p>

	<p>total claim limit (see below).</p> <p>If a donor receives bonus payments, these should only be considered if they can be shown to be a regular part of the donor's income.</p> <p>Reimbursement will be based on net income over previous 3-month period with supporting documentation from employer.</p>
<p>Responsibilities</p>	<p>Recipient Donor Nurses are expected to liaise at an early stage with the WHSSC in order to ensure that agreement is clear at an early stage of the complex planning of the donation. WHSSC will respond to the nurses promptly and with fairness and equity.</p> <p>Referrers should:</p> <ul style="list-style-type: none"> • Inform the patient that expenses are not routinely funded outside the criteria in this policy; and • Refer via the agreed pathway. <p>In all other circumstances submit an IPFR request.</p>

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1. Aim

1.1 Introduction

The document has been developed as the policy for the planning of Live Donor Expenses for Welsh patients. The policy applies to residents of all seven Health Boards in Wales.

The purpose of this document is to:

- Set out the circumstances under which patients will be able to access Live Donor Expenses services;
- Clarify the referral process; and
- Define the criteria that patients must meet in order to access treatment.

1.2 Relationship with other Policies and Service Specifications

- All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR).

2. Scope

2.1 Definition

WHSSC has the commissioning responsibility for NSCAG services for the population of Wales including transplantation and the treatment of end stage renal failure including renal transplantation.

The main clinical service involved is the operation to remove a kidney for the purpose of transplantation into a Welsh patient.

3. Access Criteria

3.1 Clinical Indications

The decision to go ahead with the transplantation is predominantly that of the Transplant Team (normally in Cardiff or Liverpool for the Welsh recipient).

3.2 Criteria for Funding

Access Criteria/Rationale

The Human Organ Transplants (HOT) Act 1989 forbids the offer of payment of any inducement for the supply of human organ. However, it does not prohibit the payment of reasonable expenses to a donor for travel and accommodation and any loss of earnings incurred if directly attributable to his / her donation of an organ.

Any payment to living donors should ensure that, within reason, the donor is no worse off as a result of the donation, but neither should they gain any financial advantage. Any payment in excess of the amount needed to reimburse losses would constitute a payment for the donation and breach the HOT Act 1989.

Loss of Earnings

The level of reimbursement will depend on any other sources of reimbursement available to the donor. Typical absence from work is usually up to 12 weeks and this may involve entitlement to full / reduced / basic / no pay.

The following positions are confirmed for each of the different categories of employment.

Employed Donors

Some employers may fully support the donor and will pay full salary to the employee throughout their absence from work. Other donors may receive full pay initially from their employers, but after a few weeks may only receive statutory sick pay. In addition, there is a third group of donors who may only receive Statutory Sick Pay from the start of their absence from work. Reimbursement is to be

calculated from of the difference between the validated claim and Statutory Sick Pay up to the total claim limit (see below).

If a donor receives bonus payments, these should only be considered if they can be shown to be a regular part of the donor's income.

Reimbursement will be based on net income over previous 3-month period with supporting documentation from employer.

3.3 Referral Pathway

The actual transplant will normally be a matter for referral between a Nephrologist and the Transplant Surgeon. In respect of the referral for funding for live donor expenses this will normally be made by one of the Recipient Nurses.

3.4 Exclusions

The procedure is only funded for patients meeting the above criteria.

3.5 Exceptions

If the patient does not meet the criteria for treatment, but the referring clinician believes that there are exceptional grounds for treatment an Individual Patient Funding Request (IPFR) can be made to WHSS under the All Wales Policy for Making Decisions on Individual Patient Funding Requests ([IPFR](#)).

If the patient wishes to be referred to a provider out of the agreed pathway, an IPFR should be submitted.

Guidance on the IPFR process is available at www.whssc.wales.nhs.uk

3.6 Responsibilities

Referrers should:

- Inform the patient that these expenses are not routinely funded outside the criteria in this policy.

If circumstances are deemed to be exceptional then an IPFR should be submitted.

4. Putting Things Right: Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided. The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern:

- When a patient or their representative is unhappy with the decision that the patient does not meet the criteria for treatment further information can be provided demonstrating exceptionality. The request will then be considered by the All Wales IPFR Panel.
- If the patient or their representative is not happy with the decision of the All Wales IPFR Panel the patient and/or their representative has a right to ask for this decision to be reviewed. The grounds for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated. The review should be undertaken, by the patient's Local Health Board;
- When a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to WHSSC.

6. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (welsh).

This policy has been subjected to an Equality Impact Assessment. The Assessment demonstrates that the policy is robust and that there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.