# SOUTH WEST THAMES RENAL AND TRANSPLANTATION UNIT

## SOCIAL WORK AND COUNSELLING INFORMATION PACK

# (FOR PATIENTS ATTENDING THE RENAL UNIT, ST HELIER HOSPITAL AND ALL SATELLITE UNITS)

For further information contact
The Social Work/Counselling Dept.,
Renal Unit
St.Helier Hospital
Wrythe Lane
Carshalton SM5 1AA

Tel: 020 8296 2940/3699

Email: Celia.Eggeling@esth.nhs.uk

**JULY 2013** 

We offer a Social Work Service to all patients attending **St.Helier Renal Unit** and its **Satellite Units.** 

Many patients will start dialysis without having come in contact with us prior to commencing dialysis treatment. If some of your concerns can be identified and addressed at an early stage of your treatment pathway, realistic plans can then be made to help you successfully integrate dialysis into your lifestyle with the minimum of disruption.

The sorts of issues people normally present with at this time are around:

- financial concerns as a result of becoming chronically ill
- insufficient means to finance increased expenditure (prescription costs/travel to hospital, childcare etc)
- employment issues
- sickness and welfare benefit eligibility
- accommodation (too small to accommodate dialysis equipment or stores, inability to manage stairs or get in/out of bath)
- care of dependents whilst patient is hospitalised or required to attend the unit
- needing help with personal care and activities of daily living

Having identified the problem, we are then in a better position to refer out to the relevant agency within your local authority to ensure that these needs are appropriately met.

## COMMUNITY SOCIAL CARE PROVISION CONTACT DETAILS

Advice on community based social care provision for patients and/or carers can be obtained from the under-mentioned:-

#### PATIENTS LIVING IN THE LONDON BOROUGH OF

 SUTTON
 :
 020 8770 5000

 MERTON
 :
 020 8545 4430

 KINGSTON
 :
 020 8547 5757

 LAMBETH
 :
 020 8926 5555

 CROYDON
 :
 020 8726 6500

 WANDSWORTH
 :
 020 8871 6000

#### **PATIENTS LIVING IN SURREY:**

Adult Social Care - 0300 200 1005 (out of hours 01483 517898)

Information on service provision can be obtained on Surrey County Council's website – <a href="https://www.surreycc.gov.uk">www.surreycc.gov.uk</a>

#### PATIENTS LIVING IN HAMPSHIRE:

Adult Social Care – Aldershot, Alton, Basingstoke – 0845 603 5630 (out of hours 0845 600 4555)

Information on service provision can be obtained on Hampshire's website – wee.hants.gov.uk or email: <a href="mailto:adult.services@hants.gov.uk">adult.services@hants.gov.uk</a>

PATIENTS LIVING IN BERKSHIRE : 0845 6014726

PATIENTS LIVING IN WOKINGHAM : 0845 6009009

PATIENTS LIVING IN WEST SUSSEX : 01243 752999

**THE COUNSELLING SERVICE** provided by the Renal Unit, aims to facilitate exploration of emotions and difficulties experienced by patients and/or their families as a result of chronic illness.

To experience disbelief, anger and despair are normal responses to loss and are part of the grieving process. Patients with renal failure have lost a part of their healthy self and need to mourn – as might their partner and family who also need time to come to terms with the effect illness had had on their lives.

Frequently expressed concerns by new and long term dialysis patients are :-

- depression
- concern about death and dying
- marital and family stress
- employment concerns
- loss of independence/role reversal
- altered body image/low self esteem
- sexual dysfunction
- issues around renal transplantation

Whilst some people prefer to work through their feelings in their own time, in their own way or with their own support network, others may prefer to speak to someone independently. Partners, carers or children may also feel they would benefit from such contact.

The counselling service exists to try to meet this need either within the Renal Unit setting or by onward referral to a more local counselling centre.

Other areas where counselling is routinely offered are :-

- **HIV COUNSELLING** (this is a requirement when patients are wishing to have holiday dialysis in other Units or waiting to be placed on the Transplant Waiting List)
- **LIVING DONOR COUNSELLING** (where family members, friends, partners or spouses have expressed an interest in donating a kidney to a loved one).

FOR FURTHER INFORMATION OR APPOINTMENTS, PLEASE CONTACT THE RENAL COUNSELLING AND SOCIAL WORK DEPARTMENT ON 020 8296 2940

#### **RENAL UNIT HIV ANTIBODY TESTING**

#### **PURPOSE OF HIV TEST**

HIV testing is a routine procedure for patients being prepared for renal transplantation or wishing to holiday at another Unit where confirmation of HIV status is a requirement.

#### INFORMED CONSENT

Prior to bloods being taken, each patient must be given an opportunity to consider the implications of submitting to an HIV test. For consent to be 'informed' a number of issues need to be considered and discussed (as recommended in the DoH Guidelines for Pre-Test HIV Testing PL/C/MO/96).

#### **GENERAL INFORMATION**

Aids is caused by a virus called HIV. This virus can damage the body's defence system so that it cannot fight certain infections and other diseases. It cannot be passed on through every day contact.

It is **not** a test for AIDS – it will only tell you if you have been infected by the virus. Your results and the fact that you have been tested are confidential – between you, the doctor and other staff directly concerned with your care.

It may take up to two weeks before the results are available and these should be fed back to you in person by medical staff. No results should ever be given out over the telephone.

A **positive** result does not mean you have AIDS – it means that you have HIV and that it can be passed on to other people in certain circumstances.

PATIENTS CONSIDERED AS A HIGH RISK would be :-

Homosexual and Bisexual men
Haemophiliacs
Recipients of blood transfusions prior to 1986
Intravenous drug abusers
Anyone having unprotected sex – particularly with people from overseas

and may wish to be seen by a Specialist HIV Screening Counsellor to discuss specific concerns. Any patient wishing to use this service should contact the GUM clinic **on 020 8296 2176** 

All other patients will be routinely seen by one of the Consultants, one of the Specialist Nurses.

### BENEFIT ELIGIBILITY INFORMATION AND EMPLOYMENT ISSUES

 FREE PRESCRIPTIONS: All patients with a 'working fistula' are exempt from Prescriptions charges. Application forms are available from your GP Surgery or a Pharmacy.

Patients not yet eligible for prescription exemption are advised to purchase a Pre-Payment Certificate which considerably reduces the cost of their medication.

- has been replaced with the Personal Independence Payment (PIP). Most people getting DLA won't be affected by PIP until 2015 or later, but there are some exceptions. You'll be asked to make a claim for PIP if after October 2013 there's a change in how your condition affects you OR your DLA award is due to end and you haven't received a renewal letter. Unless either of these things happen you don't need to do anything. You'll receive a letter in 2015 or later explaining what will happen to your DLA and how you can claim PIP.
  - PERSONAL INDEPENDENCE PAYMENT/ATTENDANCE ALLOWANCE:
    There is a strict eligibility criteria for this benefit. If in doubt, contact your local Citizen's Advice Bureau or their Central Helpline on 020 8405 3553.

PIP is most commonly awarded on the grounds that the patient needs assistance with personal care of, if under 65, has severe mobility difficulties. Being a renal patient does not automatically deem you eligible.

To qualify for PIP you must be aged 16 to 64 from 8<sup>th</sup> April. You must be having difficulty with daily living activities such as:

Preparing or eating food
Washing and bathing
Dressing and undressing
Communicating
Managing your medicines or treatments
Making decisions about money

You may get the mobility component of PIP if you need help with going out and moving around.

How to Claim:

You will need to telephone the Department for Works and Pensions for a form which will ask you how your long tem health condition or disability affects you.

PIP (new claims only) – 0800 917 2222 Attendance Allowance Helpline – 0845 712 3456 Employment & Support Allowance (this has replaced the Incapacity Benefit) – 0800 055 6688 EMPLOYMENT ISSUES: If you are unable to work as a result of your illness
or have been required to reduce your working hours because of dialysis
commitments, you may be entitled to benefits and should seek expert advice
from Citizen's Advice. Disability Employment Advisors are based at Job
Centres and will have a range of jobs and retraining information which could
get you back into the work place.

Under the **Disability Discrimination Act**, it is unlawful for employers to discriminate against disabled people, in all aspects of employment, for a reason related to their disability - unless this can be justified. The Act covers things such as :- application forms, interview arrangements, proficiency tests, job offers, terms of employment, promotion or training opportunities, work-related benefits (such as access to recreation or refreshment facilities), dismissal or redundancy. Under the DDA your employer has a duty to make 'reasonable adjustments' to make sure you are not put at a substantial disadvantage by employment arrangements or any physical feature of the workplace. Examples of such adjustments could be: - allocating some of your work to someone else, transferring you to another post or place of work, being flexible about your hours, providing training or retraining etc.

- WELFARE BENEFIT CHECKS: Your local Citizens Advice Bureau will carry out a full benefit check to determine eligibility and will assist with claim form filling. DICE (Disability Information Centre Epsom) which is based at Epsom Hospital give advice on all aspects of disability including benefit entitlement and can be contacted Mon to Friday, 10am 4.30am on 01372 735243 or by email on Dice@esth.nhs.uk
- TRAVEL EXPENSES TO RENAL UNIT: Patients on Income Support, Income
  Based ESA, Pension Credit, Working Tax Credit, Child Tax Credit or on low
  incomes who do not use hospital transport, may be eligible for
  reimbursement of public transport fares or car mileage expenses. Relevant
  application forms can be obtained from the Cashier, St.Helier Hospital. Proof
  of benefit eligibility will be required together with petrol or transport receipts.
- LONDON TAXICARD SCHEME allows London residents with mobility impairment which prevents them from using buses or trains, to travel in the contractor's licensed radio taxis black cabs or Private Hire Vehicles at subsidised rates. Contact your local authority for further details
- THE NATIONAL KIDNEY FEDERATION RUNS A HELPLINE FOR PATIENTS/CARERS Tel: 0845 6010209. Email : <a href="mailto:nkf@kidney.org.uk">nkf@kidney.org.uk</a>. Website <a href="www.kidney.org.uk">www.kidney.org.uk</a>

#### INSURANCE ADVICE

a) CAR INSURANCE: The DVLA and the patient's own insurance company should be informed of any significant changes in the patient's health. This includes commencement of dialysis and/or date of transplant. They do not restrict the period of the licence but keep the information on file in case it is ever requested by a third party insurance company. Contact the Drivers Medical Group, DVLA, Swansea, SA99 1TU on 0300 790 6806 or by fax 0845 850 0095. Further information is available from www.direct.gov.uk/motoring.

If an insurance company is not advised of the patient's dialysis status, they may refuse to meet any claims which are made.

**b)LIFE COVER/MORTGAGE ADVICE:** Contact the following for up to date information:

BKPA : Tel: 01420 472021 NFKPA : Tel: 01909 487795 NKRF : Tel: 01480 454828

c) HOLIDAY INSURANCE: It is important that you don't book your holiday until you have taken out holiday insurance which covers you for a pre-existing medical condition. A full list of companies has been compiled by the NKFPA and it has been noted that Mars Insurance Brokers 020 8366 2222 specialise in pre-existing conditions.

Stackhouse Polland (Insurance Brokers to the BKPA) offer travel, home and motor insurance and can be contacted on **Freephone 0500 720000**. Remember to mention BKPA when you call.

The NKF have a list of insurance companies which can be downloaded from their website <a href="https://www.kidney.org.uk">www.kidney.org.uk</a>

Two other things to remember are:

In Europe, in addition to the correct holiday insurance, you should also carry a completed E111 form.

If you are on a Transplant Waiting List, many insurance companies will assess you as being on a 'Hospital Waiting List' awaiting an operation – and this may affect your holiday insurance premium.

#### **RENAL CHARITIES**

It is recognised that Renal patients often face loss of earnings and increased costs as a result of being dialysis dependent.

The following charities can be approached for grants and amenities:

- The British Kidney Patient Association (BKPA)
- The National Kidney Research Fund
- St.Helier and Surrey Kidney Patient Association

The St.Helier and Surrey Kidney Patients Association is devoted to improving facilities and treatment of our renal patients.

Membership forms and information leaflets detailing the help which is available to members, are available on the Unit or from the Chairman: –

Mr.D.A.Spensley L'Alise Guildford Road Godalming Surrey GU7 3BX

Tel: 01483 426276

Please contact us in confidence if you wish to make an application.