University Hospitals Coventry and Warwickshire NHS Trust

PSYCHOLOGICAL ISSUES FOR PATIENTS WITH CHRONIC KIDNEY DISEASE	
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Original Author's Name, Title & email address:	Dr Julie Highfield Clinical Psychologist (2010- 2012)
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Responsible Director's Name & Title:	Dr. Simon Fletcher
Department / Specialty:	Renal Services
Target audience:	Renal Service Staff
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Version	Title of Trust Committee/Forum/Body/Group consulted during the development stages of this Trust-wide Clinical Guideline	Date
1	Renal Services Protocol and Guideline Approval Group	1/4/10
2	Renal Services Protocol and Guideline Approval Group	14/3/12
3	Renal Services Protocol and Guideline Approval Group	5/3/14
4	Renal Services Protocol and Guideline Approval Group	3/2/16

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1.0 SCOPE

1.1 This guideline is for all clinical staff involved in the care of chronic and end stage renal failure renal patients. It is intended to guide the awareness of psychological issues, the assessment, the day-to-day support and onward referral to internal Clinical Psychology services or community services as appropriate.

2.0 INTRODUCTION

2.1
The National Service Framework for Renal services, parts one and two *(2004, 2005)* state that psychological support for patients and carers is considered an important part of the care pathway (at all stages, dialysis, transplantation, chronic kidney disease, end of life care).

- **PART ONE** Psychological input recommended as part of standard one: patient centred-care, standard two: preparation and choice, standard five: transplantation:
    - to develop strategies to deal with psychological consequences of illness.
    - Importance of education in preventing depression.
    - Need for psychological support identified through individual care-planning.
    - psychological preparation for transplantation and dialysis (at least 1 year prior) e.g. procedures, risks and benefits
    - Assess psychological suitability for preferred renal replacement therapy
- **PART TWO:**
    - Quality requirement four: psychological needs considered as part of end of life care

According to the Chronic Kidney Disease guideline of the National Collaborating Centre for Chronic Conditions (2008), psychological support should be available from CKD stages 4 onwards.

The recommendations of the National Renal Workforce Planning Group (2002) outlines the need for an awareness of psychological issues in renal patients, and outlines the roles of Clinical Psychologists and Renal Counsellors within renal services. At UHCW we currently have 0.6WTE Clinical Psychology Input to the service, covering every renal patient across the whole of Coventry and Warwickshire.

Not all patients with distress are appropriate for referral to Renal Clinical Psychology, as figure 1 outlines (appendix 2). The understanding and management of psychosocial issues for all patients is an important part of our care within Renal Services. It is the responsibility of all staff to be aware of and support patients through listening, advice giving, education and referral on for specialist intervention with the Clinical Psychologist, or community services, if needed.

It should be noted that the Clinical Psychologist's role is not limited to offering on-to one input to patients. As an appropriate response to the high demand for psychological services in renal units in the face of very limited human resources, another significant role of the clinical psychologist is to develop and supervise the delivery of appropriate routine psychological care by all renal unit staff. This may be via ward based clinical supervision with direct care staff, training courses e.g. managing challenging behaviour, understanding why patients find it difficult to change their behaviour, and patient focused clinical consultancy to multi-professional teams.

3.0 STATEMENT OF INTENT

3.1 This document outlines the issues that all staff need to be aware of at each stage of care, and the Guideline for referral on for further specialist intervention.

4.0 DEFINITIONS

4.1 NONE

5.0 DUTIES / RESPONSIBILITIES

5.1 It is expected that:

- all staff will have an awareness of this guideline
- all staff will follow the "level one psychological support" guidance within this document
- staff referring to Renal Clinical Psychology will have read this guideline to consider how appropriate the referral is, or if another community service would be better placed to offer input.

6.0 DETAILS OF THE DOCUMENT

6.1 Development of the guideline

The Guideline was developed following one year of Clinical Psychology input having been provided to the Renal Service. It arises from reflection on the way in which Clinical Psychology has been accessed by the Renal Service and identified needs for the Service. The consultation process was met by sending drafts for comments initially to the Lead Clinical Psychologist at UHCW, and then to the senior haemodialysis team and members of the Renal Services Guideline and Guideline Approval Group.

6.2 Application of the Guideline

The individuals that will benefit from the implementation of this Guideline will be as follows:

Renal patients: pre-dialysis, dialysis, transplant recipients and their live donors will benefit from the increased confidence and competency of clinical staff in recognising and containing mild distress and recognising clinically significant distress and when to refer on to the Clinical Psychologist or other appropriate services.

Nursing and Medical Team: the staff will have a reference tool for identifying and managing psychological distress, and will have a clear pathway of referral to the Clinical Psychology Service.

6.3 Objectives of the Guideline

This Guideline applies to all renal patients at each stage of their disease. The process will follow and identify the objectives of the Guideline, which include recognizing and managing psychological distress appropriately and effectively.

6.4 Guideline Steps

The Guideline allows the Clinical Team to consider psychological distress at each level of the disease process, with clear questions to use as part of the overall assessment, and guidelines on how to manage appropriate levels of distress, and how to identify those patients with difficulties that may benefit from a psychological assessment.

6.5 Guideline

6.5.1 Understanding the Psychological Reactions to Renal Failure

It is normal for patients to experience the following in response to a change in their health status, or a diagnosis of renal problems:

- Shock
- “Denial”
- Worry
- Anger/ frustration
- Low mood
- Confusion
- Uncertainty
- Dealing with losses

Kimmel 2002 and Christensen and Ehlers 2002

It is not always helpful to assume that emotional responses are worrying, or require a psychological intervention. Often the patient needs time and the general support of the team to come to terms with health problems. As long as the patient continues to move through these emotions then this is not of concern.

"Denial"

- Can be protective
- Sometimes people do not want to attend appointments/ take medication/ come for dialysis
- Things are avoided because it feels surreal or overwhelming

Anger:

- Is part of a normal adjustment reaction
- May be related to fear or confusion

Worry/ Anxiety:

- Can be motivating, and help a patient to seek information
- Agitation can be part of the build up of toxins in the blood pre-dialysis
- Worrying may be a way that the patient has always coped and is not necessarily indicative of a problem
- Chronic or persistent anxiety, panic and trauma can be assessed for using the information below

Low mood:

- It is common to experience low mood as an adjustment to the losses as part of being a renal patient
- Pervasive low mood can be assessed by using the information below

6.5.2 Psychological issues across the phases of renal disease.

Psychological issues may differ at each stage of treatment, so it may be worth considering the following:

Pre-dialysis

Patients may be feeling vulnerable, confused, and anxious about the future.
They may be experiencing some post traumatic stress if they have "crash-landed" into the renal service.

At this stage there is a need for establishing contact and a relationship with the service.
Patients require information, but it may be important to consider how much and how often. Each patients need will vary and it is useful to ask the patient what would best suit them.

Dialysis

Patients may have distress related to feelings of being passive, controlled by the dialysis regime and fluid and dietary restrictions. They may feel fatigued and have a reduced role at work or socially, which may have an impact upon their sense of self-worth. (Kimmel 2002)
This is a time where people may feel hopeless and depressed. There may also be anxiety in the early stages related to health, or to the procedures involved in dialysis.

At this stage it is important to normalize that many people find this difficult, and give information about how to dialyse to live rather than to live to dialyse. Encourage the patient to seek support and to engage in coping strategies that have helped them before.

Pre and Post Transplant, including donors

Despite feeling free from dialysis, patients often report feeling fear in anticipation of their transplant failing. If a live-related transplant, this can lead to some changes in the dynamics of the relationship with the donor,

and can be a cause of tension during the transplantation process. Some patients who have been on dialysis for a long time may have difficulties adjusting to a new routine. Both donors and recipients can struggle when the changes post-transplant might not meet their initial expectations.

At this stage, again information is important, so that the patient is clear about what to expect. The on-going post transplant support that the team provides is a useful forum for monitoring the individual's psychological well-being, and allowing a person to feel psychologically prepared for transplant or donation.

Palliative and Conservative Care

For some patients, active medical management is deemed inappropriate, or for others they may wish to withdraw from treatment. Such patients may not necessarily experience distress as a result of this, and may in fact feel relieved that their wishes have been respected.

At this stage, the routine support that staff provide should be sustained, and specialist psychological intervention is not beneficial. However, the team may benefit from an opinion from Clinical Psychology when the reasons for withdrawal from treatment appear to be linked to underlying psychological difficulties or distress.

6.5.3 The initial assessment of a patient: Senior Staff

According to the Chronic Kidney Disease guideline of the National Collaborating Centre for Chronic Conditions (2008), the following should be including when educating CKD patients:-

- What people can do to manage and influence their own condition
- Information about the ways in which CKD and the treatment may affect people's daily life, social activities, work opportunities and financial situation, including benefits and allowances available
- Information about how to cope with and adjust to CKD and sources of psychological support
- Drugs that should be used with caution or at reduced dose in people with CKD

USEFUL THINGS TO CONSIDER IN AN ASSESSMENT

When the patient is first identified to the team, it is useful to be aware of the following to increase our understanding of the patient. All senior clinical staff are encouraged to ask about the following at initial assessment:

- Patient's perception of current/ impending illness
  - The impact of the illness upon his/her life
  - The meaning of the illness to the patient.
- Does the patient prefer to be given full information about their illness?
- Does the patient like to be told what they can do to manage their illness?
- The patient's support system (partner, friends, family etc)
- How does the patient describe their typical coping style? How have they coped with other major life events in the past? Does s/he report a tendency to problem solve and think things through, do they tend to avoid issues, to they tend to discuss things with their family, will they allow themselves to cry and express emotions?
- Patient's ability to calm themselves down when distressed
- Patient's history of anxiety and depression

- Any substance abuse or dependency

Screening for distress:

General Screening questions

If you feel the patient is experiencing distress, the following questions may help you:

1. How do you feel you are coping just lately?
2. Have you noticed any changes in your mood of late?
3. Have you been feeling low?
4. Have you been feeling more worried than usual?
5. Have you been experiencing changes in
    a. Sleep
    b. Appetite
    c. Motivation
    d. Enjoyment
    e. Ability to take part in usual activities

It may be useful to consider the use of the Distress Thermometer to consider the difficulties in more detail.

6.5. 4 Levels of Psychological support

Please refer to figure 1.

6.5.4.1 Level one psychological support: All Staff

There are things the nursing and medical team may do in routine practice to promote psychological well being in patients. Staff should consider the following:

- Please use the guidelines above to help you assess the situation
- Psychological problems are common. Given restrictions and impact on quality of life we should celebrate how resilient the majority of people are in managing this condition to the best of their abilities (Petrie 1997)
- Normalisation. Telling the patient what to expect in terms of future concerns and distress regarding their health. This is normal and will improve over time.
- Encourage use of familiar strategies, reminding the person about their coping strengths.
- Relaxation techniques may be taught by the nurse, in terms of simple breathing techniques. Encourage restful activity, and “time off” from being a renal patient.
- Provide patient and family support: it is not always about having the right things to say, it is often about being willing to listen.
- Discuss the traumatic health event, and encourage the patient to discuss this with the family and others.

- Encourage patients to take some control
  - seek out information
  - ask questions
  - take an active part in looking after their health: diet, medications, dialysis

- Encourage Flexibility: there may be irritations along the way, but encourage patients to use their energy for the more important things.

- Encourage the patient to set goals, and have something to look forward to.

- Do not be hard on patients, or encourage them to be hard on themselves for not managing to be the "perfect patient".

- Patient may be referred to other healthcare professionals for issues of depression, smoking, alcohol abuse, spiritual needs.

- For current inpatients, it may be advisable to use a watchful waiting approach and wait to see if these problems subside after some time, or discharge from an acute stay in hospital.

- Consider giving the patient the Clinical Psychology leaflet on the emotional impacts of renal problems (available on the e-library).

6.5.4.2 Level two: Counselling

This is offered by more senior, experienced, or trained members of the renal team.
Examples may be the role of a Renal Nurse Specialist in assisting a person in their decision about dialysis.

6.5.4.3 Level three Psychology:

A referral to the Clinical Psychologist is appropriate when there are significant levels of distress, or psychological factors play a part in the management of the patient. Sometimes people need psychological input to help them makes sense of their disease or the information they have been given. A systematic psychological intervention is useful in reducing psychological distress in the renal patient (Hener et al, 1996)

What is a Clinical Psychologist?

A Clinical Psychologist is an applied psychologist, drawing on a range of
theoretical and scientific evidence-based approaches in their delivery of care. A Clinical Psychologist offers psychological assessment and intervention for renal patients, their carers and families. In addition, clinical supervision, consultation, and training is provided for direct care staff, as well as conducting research, audit and service evaluations.

The University Hospitals Coventry and Warwickshire have a 0.6 WTE Clinical Psychologist, providing a service to patients across Coventry and Warwickshire. Referrals may be received from Consultants, senior nursing staff, and allied health professionals. Referrals may be of patients from pre-dialysis, haemodialysis, CAPD, transplant and inpatient sources.

When to refer to Clinical Psychology

If the problem seems more complex, it may be useful to consider a referral to the Clinical Psychologist for an assessment.

Reasons for referrals include:

- Psychological opinion required to aid medical management
- Anxiety
- Depression
- Specific phobias
- Trauma reactions
- Difficulties in adjusting to and coping with care regimes and treatments
- Associated behavioural and habit problems
- Difficulties people encounter in their home, work and hospital relationships as a consequence of renal problems and treatment.

This assessment may then lead to:

- A formulation of the patient's psychological distress, which will be discussed with the appropriate members of the team to inform the patients care
- Brief advice to the patient
- Possible referral on to other appropriate services
- A brief psychological intervention, drawing on a range of theoretical perspectives, e.g. cognitive – behavioural, psychodynamic, systemic.

How to refer to Clinical Psychology

1. Discuss the possibility of referral with the patient, and make sure the patient consents
2. Discuss the referral with the Clinical Psychologist, to see if an assessment would be appropriate
3. Complete a referral form (see end of guidelines)
4. Be aware there may be some wait for a routine assessment, so please indicate the urgency of the assessment
5. incomplete referral forms will be returned and this will delay the individual being placed on the waiting list

What is Depression?

Has the patient been experiencing:

- low mood for more than 2 weeks that has significantly impacted upon their ability to function
- a lack of ability to experience pleasure or enjoyment in their usual activities
- decreased motivation
- discouraged about the future
- feelings of hopelessness
- They criticize themselves
- They have any thoughts of suicide

→ consider using the Hospital Anxiety and Depression Scale, or the PHQ-9 as a tool

What is Anxiety?

Have the patient experienced:

- Worrying thoughts going through their mind
- feeling tense, or unable to relax
- feeling restless
- butterflies in the stomach
- Feelings of panic
- Is the patient misinterpreting bodily sensations as sinister and as indications of health problems despite reassurances?

→ consider using the Hospital Anxiety and Depression Scale or PHQ-9 as a tool

What is Post-traumatic Stress?

Ask the patient if

- They feel persistently nervous or agitated

AND

- Intrusive memories/ pictures of a traumatic event occur during dreams or daytime
- They find themselves avoiding anything that reminds them of the event, including talking about it.

→ consider using the Impact of Events Scale as a tool

Substance Abuse

Is the patient taking any substances of overusing alcohol, which is affecting their health?
Try to establish what may be the triggers for use.
→ consider a referral to the community drugs or alcohol services

Cognitive problems

Is the patient finding it hard to carry out their usual everyday tasks because of problems with memory or thinking?

→ consider assessing formerly with a cognitive screen, or making a referral for this.

6.5. RISK

In the event of suspected suicide risk:

Ask the patient clearly if they have thought about harming themselves or taking their own life.

1. If YES, ask them if they have made any plans.
2. If YES, ask what the likelihood is of them carrying these out.
3. Also assess if they have made previous attempts on their life in the past.

If a suicide risk seems high, then tell the patient you have a duty of care to let their general practitioner/other responsible person know of your concerns, and if there is any other person whom they would wish you to contact to make them aware of your concerns.

- contact the person's GP on the same day
- Contact the local Crisis Team on the same day and make a referral (phone numbers below)
- Inform your line manager and the Clinical Psychologist.
- If an inpatient, call Liaison Psychiatry (Caludon Centre, ext 28100, or the Mental Health Liaison Nurses ext 27870)

If the risk is low, then spend some time normalizing this with the patient, but also inform patient of the Crisis Team number which is a 24 hour service which they may contact if feeling at risk of suicide. Ask patient to contact their GP if the suicidal ideation becomes worse. Continue to ask patient at intervals throughout their care.

Coventry : 02476 961100

Rugby: 01788 663213

North Warks: 02476 310037

Warwick: 01926 450660

Stratford: 01789 415440

7.0 DISSEMINATION AND IMPLEMENTATION

7.1 The Guideline will be implemented by dissemination of the document to all the clinical areas in the Renal Service and placed on the e-library system at UHCW.

8.0 TRAINING

8.1 All new band 5 nurses are introduced to the guideline as part of their introductory training.

9.0 MONITORING COMPLIANCE

10.1 Monitoring Table

The usefulness of the Guideline will be reviewed by the Renal Clinical Psychologist and the Renal Services Approval Group.

Aspect of compliance or effectiveness being monitored	Monitoring method	Individual department responsible for the monitoring	Frequency of the monitoring activity	Group / committee which will receive the findings / monitoring report	Group / committee / individual responsible for ensuring that the actions are completed
Referral Form used effectively for all referrals	Audit	Clinical Psychologist	6 months	Clinical Psychologist will identify if referral forms not completed	Clinical Psychologist and Clinical Leads

10.0 STAFF COMPLIANCE STATEMENT

All staff must comply with this Trust-wide Clinical Guideline procedure and failure to do so may be considered a disciplinary matter leading to action being taken under the Trusts Disciplinary Procedure. Actions which constitute breach of confidence, fraud, misuse of NHS resources or illegal activity will be treated as serious misconduct and may result in dismissal from employment and may in addition lead to other legal action against the individual/s concerned.

A copy of the Trust's Disciplinary & Appeals Procedure is available from eLibrary.

Clinical Guidelines assist in decision making; they do not replace clinical judgement. Regardless of the strength of the strength of evidence, it remains the responsibility of the clinician to interpret the application of the clinical guidance to local circumstances and the needs and wishes of the individual patient. Where variations of any kind do occur, it is important to document the variations and the reason for them in the patient's health record.

11.0 EQUALITY & DIVERSITY STATEMENT

Throughout its activities, the Trust will seek to treat all people equally and fairly. This includes those seeking and using the services, employees and potential employees. No-one will receive less favourable treatment on the grounds of sex/gender (including Trans People), disability, marital status, race/colour/ethnicity/nationally, sexual orientation, age, social status, their trade union activities, religion/beliefs or caring responsibilities nor will they be disadvantaged by conditions or requirements which cannot be shown to be justifiable. All staff, whether part time, full-time, temporary, job share or volunteer; service users and partners will be treated fairly and with dignity and respect.

12.0 UHCW ASSOCIATED RECORDS

12.1 None

13.0 REFERENCES AND BIBLIOGRAPHY

13.1 References

Christensen, A. and Ehlers, S (2002) *Psychological factors in end-stage **renal** disease: and emerging context for behavioural medicine research* Journal of Consulting and Clinical **Psychology** 70 (3) pp 712 - 724

Hener, T., Weisenberg, M. and Har-Evan, D. (1996) *Supportive versus cognitive-behavioural intervention programs in achieving adjustment to home peritoneal kidney dialysis* Journal of Consulting and Clinical **Psychology** 64 pp 731 - 741

Kimmel, P. (2002) *Depression in patients with chronic **renal** disease: What we know and what we need to know.* Journal of Psychosomatic Research 53 (pp 951 – 956)

National Service Framework for Renal Services, Parts one and two (2004, 2005)

National Collaborating Centre for Chronic Conditions. *Chronic kidney disease: national clinical guideline for early identification and management in adults in primary and secondary care*. London: Royal College of Physicians, September 2008.

Recommendations of the National Renal Workforce Planning Group (2002) The Renal Team. A Multi-Professional Renal Workforce Plan for Adults and Children with Renal Disease British Renal Society

14.0 EVIDENCE BASED REFERENCES

(If there are none, write NONE)
Properly reference sources of evidence that underpin the procedural document) ***(Delete upon insertion of text)***

14.1

References	Grade of evidence (See Table 1.)
Christensen, A. and Ehlers, S (2002) *Psychological factors in end-stage **renal** disease: and emerging context for behavioural medicine research* Journal of Consulting and Clinical **Psychology** 70 (3) pp 712 - 724	3
Hener, T., Weisenberg, M. and Har-Evan, D. (1996) *Supportive versus cognitive-behavioural intervention programs in achieving adjustment to home peritoneal kidney dialysis* Journal of Consulting and Clinical **Psychology** 64 pp 731 - 741	2
Kimmel, P. (2002) *Depression in patients with chronic **renal** disease: What we know and what we need to know.* Journal of Psychosomatic Research 53 (pp 951 – 956)	3
National Service Framework for Renal services, Parts one and two (2004, 2005)	1
National Collaborating Centre for Chronic Conditions. *Chronic kidney disease: national clinical guideline for early identification and management in adults in primary and secondary care*.	1

London: Royal College of Physicians, September 2008.	
Recommendations of the National Renal Workforce Planning Group (2002) The Renal Team. A Multi-Professional Renal Workforce Plan for Adults and Children with Renal Disease British Renal Society	1

Table 1

Grade of evidence	Based on
1	Systematic review or meta-analysis
2	Randomised controlled trial/s
3	Controlled study without randomisation (e.g. case controlled) or quasi-experimental study, such as a cohort study
4	Descriptive studies such as case series and reports.
5	Expert opinion, narrative review

14.2

Evidence supporting recommendations		
	Yes	No
Are there any relevant Cochrane Reviews related to this topic area?	☐	☒
	Yes	No
Has this been fully incorporated?	☐	☒
	Yes	No
Is there any relevant NICE guidance related to this topic area?	☐	☒
	Yes	No
Has this been fully incorporated?	☐	☒
	Yes	No
Is there any relevant RCOG guidance related to this topic area?	☐	☒
	Yes	No
Has this been fully incorporated?	☐	☒
	Yes	No
Is there any relevant RCM guidance literature related to this topic area?	☐	☒
	Yes	No
Has this been fully incorporated?	☐	☒
	Yes	No
Is there any other relevant national guidance related to this topic area?	☒	☐
	Yes	No
Has this been fully incorporated?	☒	☐

15.0 APPENDICES

15.1 **Appendix 1**

RENAL CLINICAL PSYCHOLOGY REFERRAL FORM

Please send to:
Dr Helen Love,
Renal Services, 5th Floor East Wing,
UHCW,
Clifford Bridge Road,
Coventry CV2 2DX.

Email: helen.love@uhcw.nhs.uk
Tel: 02476 968 270 (internal ext 28270)

For Office use only
Referral received on:
Date of first attempt at contact:
Date of "Relationship to Help":
Outcome: Appointment offered / not offered: Reason:
Date of first appointment:
Outcome: DNA One off / discharge Follow up
Discharge date:

DATE OF REFERRAL:

1.PATIENT INFORMATION:

Who is the referral for?: renal patient / relative	
Name:	**Date of birth:**
Hospital Number:	**NHS Number:**
Address:	**Contact telephone numbers:** **Landline:** **Mobile:**

2.REFERRER INFORMATION:

Referrer name:	**Profession:**
Contact telephone number:	**Email:**

3.RELEVANT BACKGROUND INFORMATION:

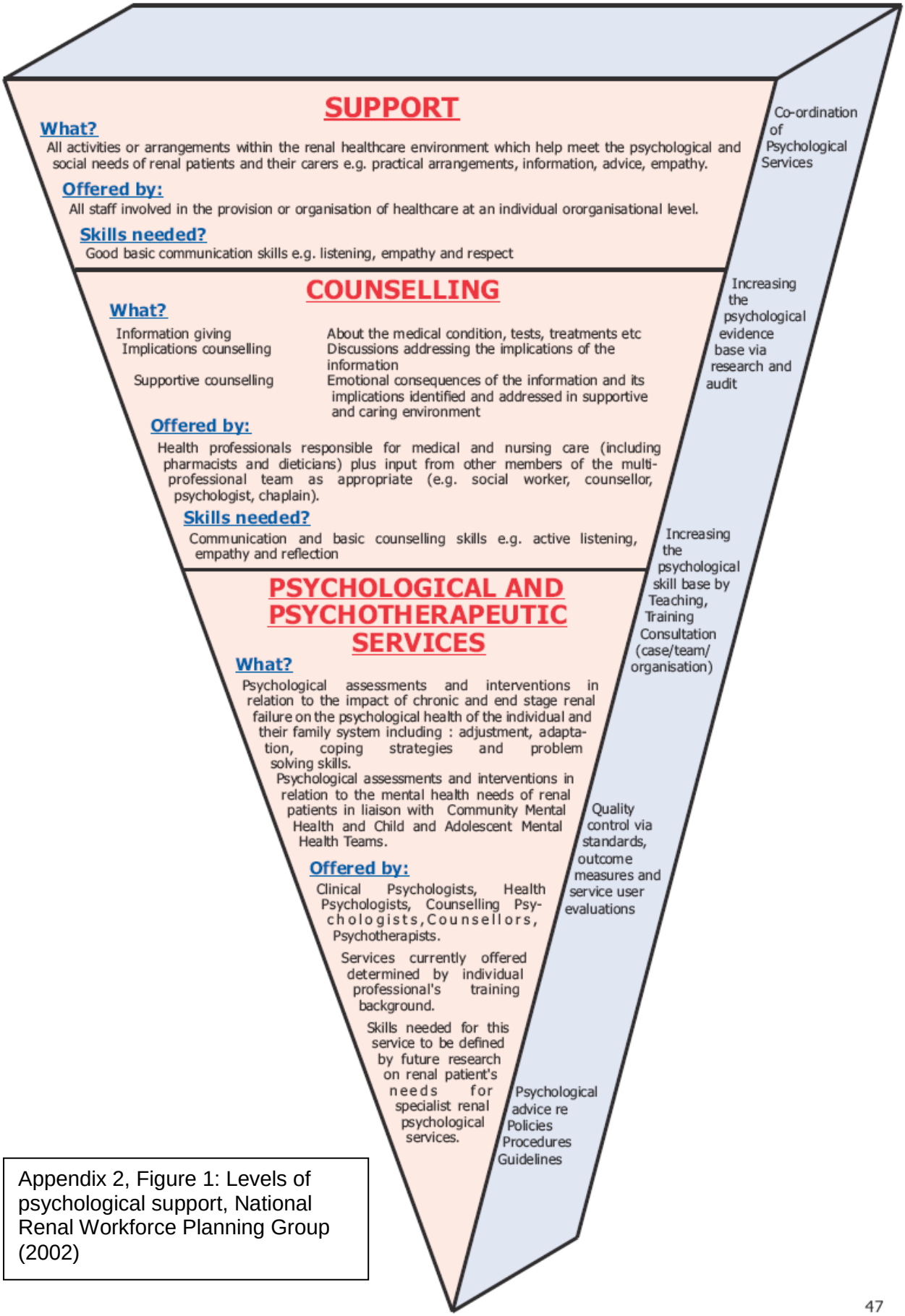
GP Name: **Address:** **Telephone:**	**Patient's renal consultant:**
	Is a translator required?: Yes / No **Language**
Details of other professionals and agencies involved: e.g. other members of Renal team Other medical teams Community mental health / IAPT Psychiatry Social services	
Diagnosis, relevant medical history and current renal care:	

Location for renal care (please circle and specify location if applicable) **In patient: Ward 50: Other ward:** **Outpatient: Low clearance: Location: Transplant: live/ cadaveric (please** **Haemodialysis: Location: circle)** **Peritoneal Dialysis donor/ recipient (please circle)**

4. REASON FOR REFERRAL TO CLINICAL PSYCHOLOGY

Please give as much information as possible; what are the patient and / or referrer hoping for from a referral to clinical psychology?	
Is the patient aware that a referral has been made to clinical psychology? Yes/ No	**Has the patient agreed to be contacted by the clinical psychologist? Yes / No**

Any other information:



Appendix 2, Figure 1: Levels of psychological support, National Renal Workforce Planning Group (2002)