



## PSYCHOSOCIAL PRACTITIONERS: PSYCHOLOGISTS, COUNSELLORS, PSYCHOTHERAPISTS, SOCIAL WORKERS: ADULT AND PAEDIATRICS

This chapter is a joint collaboration by the three psychosocial professional groups: British Association of Social Workers (BASW) Renal Social Work Group; Renal Psychologists' Network and RPT (Renal Psychological Therapists Group)(Renal counsellors, psychotherapists and counselling psychologists).

### 5.1 ADULT SERVICES

#### Introduction

The combination of complex psychological and physical health needs of people living with kidney disease means they are a group with high psychological vulnerability. Rates of clinical depression have been found to range from 20-40% across CKD, dialysis and transplant groups<sup>1,2</sup> and suicide rates in the renal population are significantly higher than the general population, with a recent study finding a 140% increase in suicide for patients receiving haemodialysis.<sup>3</sup> In addition, psychological distress is reported in 30-60% in pre-dialysis, dialysis and transplant patients and is broader in definition than just clinical depression as it includes other psychological conditions such as anxiety disorders, phobias (including needle phobia), obsessive compulsive disorder, body image issues, eating disorders, post-traumatic stress disorder, adjustment disorder and neurological impairments.<sup>4,5</sup> There is increasing evidence to show the impact of psychological problems on morbidity, mortality and healthcare utilisation.<sup>6</sup> It is vital therefore, that specialist psychosocial provision is integrated within renal units in order to provide the appropriate level of support for the complexity and chronicity of psychological needs. Evidence demonstrates that care delivered by a multi-professional team that includes psychosocial specialist professionals leads to improved medical outcomes, timely commencement of dialysis with working vascular access and reduced mortality for people living with kidney disease.<sup>7</sup> The Improving Access to Psychological Therapies report (IAPT)<sup>8</sup> for long term conditions has identified that people receiving renal dialysis should have their psychological support and interventions delivered within the kidney care setting.

#### Workforce planning recommendations

Core specialist renal professionals available should include a psychologist (clinical, counselling or health), a counsellor or a psychotherapist, and a social worker. It is recommended that a youth worker (or similar) is employed as part of the multi-professional team to support transition and young peoples' needs.<sup>6</sup> Further information is provided in the paediatric section of this chapter.

#### 2018 psychosocial workforce plan

An extensive mapping exercise was carried out to examine the current levels of psychosocial support across renal units in the UK. Full details are available in the mapping exercise report.<sup>6</sup>

##### Psychological support

Evidence for proposed staffing levels is drawn from a number of sources, primarily research evidence and comparisons to other equivalent long-term conditions (Cystic Fibrosis and cancer care), which have established psychological support within the specialist multi-professional team.

Within Cystic Fibrosis (CF) Services, the recommended level for psychologists is 1.0 WTE per 150 CF patients. This is based upon a model that all CF patients require annual input from a psychologist.<sup>9</sup> Within cancer care, a different, stratified model for psychological provision has developed based on four levels of care.

Level 1 general support is provided by all staff and Level 2 support is provided by specialist nurses, who have received additional training and supervision (provided by Level 3/4). Recommended levels of trained mental health/psychological support professionals (Level 3 counsellor/psychologist and level 4 psychologist/psychotherapist/psychiatrist) are based on research that 15% of cancer patients will need Level 3 support and 10% will need Level 4 intervention.<sup>10</sup> This is equivalent to 1.0 WTE per 600 cancer patients.<sup>11</sup>

The UK Renal Psychosocial Workforce Mapping Exercise<sup>6</sup> highlights a model for psychological support staffing levels based on a stratified acuity model of 1.0 WTE (0.6 WTE at Level 3/0.4 WTE at Level 4) for every 600 RRT patients (dialysis and transplant patients). This was based only on renal replacement therapy patient numbers. It, therefore, does not include patients for whom specialist psychological input is also required in the following groups; low clearance, general nephrology and conservative management, acute kidney injury, live donor (including altruistic assessment) and support for families or carers. This should be considered when planning staffing levels for counsellors/psychotherapists/psychologists into renal units (see recommended minimum and gold standard levels below).

**The recommended minimum level of psychological provision for a renal service is 1.0 WTE (0.6 WTE at Level 3/0.4 WTE at Level 4) for every 600 RRT and pre-dialysis patients.** This would enable up to 25% of all CKD stage 4/5 patients to access support in any year.<sup>6</sup> This level of staffing would not extend to wider services such as living donor assessment (see below).

**The gold standard level of psychological provision for a renal service is 1.0 WTE (0.6 WTE at Level 3/0.4 WTE at Level 4) for every 375 RRT/pre-dialysis patients.** This would enable up to 40% of all CKD stage 4/5 patients to access support in any year (consistent with research based rates of distress in CKD populations) and would enable the provision of a wider service to include general nephrology and conservative management, acute kidney injury, live donor (including altruistic assessment) and support for families or carers.

#### Social work support

Recommended levels of social work support staffing are considered separately to psychological support staffing. In line with the CF workforce recommendations for social workers, current practice recommends that all patients should be provided with routine input from a social worker.<sup>7</sup>

**The recommended minimum levels for social work provision are a maximum yearly caseload of 150 patients per 1.0 WTE level 3/4 worker with a gold standard of 1.0 WTE per 140 RRT patients.<sup>6</sup>**

#### Smaller units

In smaller units, where the population size would not warrant a specific psychosocial/psychological practitioner post, consideration should be given to the model that already exists in some areas of sharing of posts across chronic and long-term conditions.<sup>6</sup>

Levels of practice for all three psychosocial professional groups according to the NHS Skills for Health Career Framework are outlined in Table 4 (later in this section on page 49).

## 5.2 ADULT PSYCHOLOGISTS (CLINICAL, HEALTH AND COUNSELLING)

### Introduction

Renal psychologists (clinical, counselling and health psychologists) are highly trained doctoral level professionals. They aim to reduce distress, promote optimal development, improve psychological well-being and improve health outcomes for patients. They apply psychological theory and models to the context of physical health, chronic illness and renal disease across the lifespan. This specialist knowledge base is used to design, implement and evaluate psychological services into kidney care.<sup>12,13</sup> Renal psychology developed within both adult and paediatric renal teams from the early 1970s onwards.<sup>14</sup>

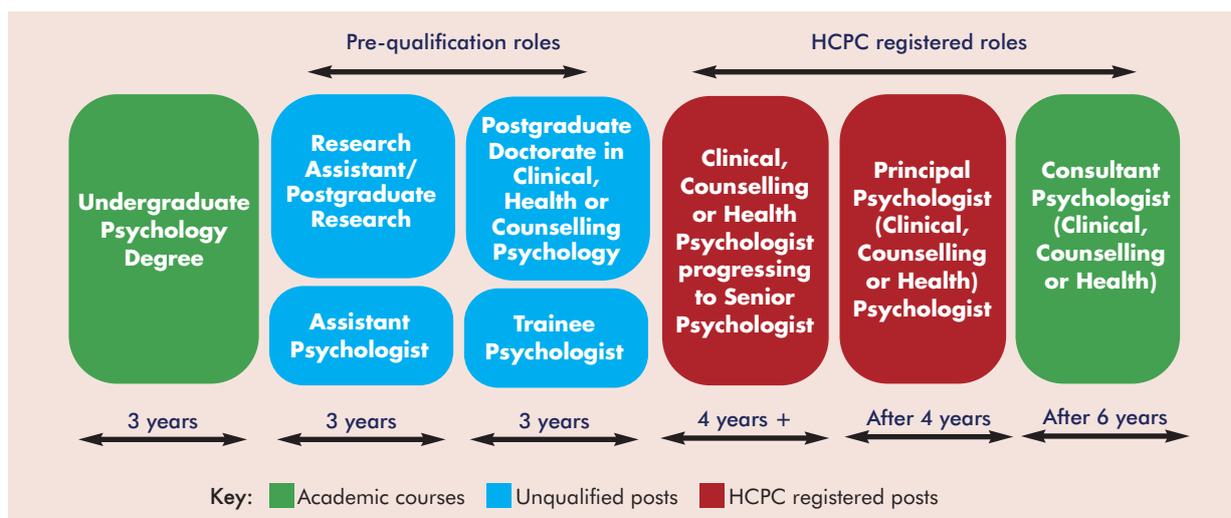
Renal psychologists are not just clinical therapists and, therefore, work at several different levels:

- Direct evidence based clinical work with patients and their families referred because of identified concerns, or those who are considered at risk of developing psychological difficulties;
- Consultation, joint work and education with other members of the renal multi-professional team involved in the patient's care to deliver psychological care;
- Undertaking a leadership role and participating at a strategic service, and policy level to promote psychologically informed care and health outcomes;<sup>12</sup>
- Conducting audit, research studies and evaluation to improve renal patient care and outcomes.<sup>12,13</sup>

The New frontier for integrated care report by The Kings Fund indicates that clinical psychologists should be embedded within physical health multi-professional teams to provide psychological support.<sup>15</sup> The need for renal psychology is identified in the service specifications for both adult and paediatric renal services.<sup>16-20</sup>

The majority of psychologists currently working in renal units are clinical psychologists.<sup>6</sup> However, some services have health or counselling psychologists employed within their units. In order to establish and lead a renal psychology service (where there are significant management, consultancy, research and service development responsibilities) a greater level of experience and post qualification training would be required, and this should be provided by a consultant psychologist.<sup>21</sup> The career pathway (Figure 1) below outlines the different training and career progression involved for these three professions.

FIGURE 1. CLINICAL, HEALTH AND COUNSELLING PSYCHOLOGY CAREER PATHWAY



The recent renal workforce mapping exercise (2017) reported 51 psychologists in post (27.2 WTE), an increase from the number reported in the 2002 Workforce Planning document (7=2.5 WTE) across adult renal services. Alongside this increase in psychologists employed in renal units, patient numbers have also increased. There is still significant variation across renal units and the 2017 figures are significantly less than the 2010 projected need for 168 psychologists (60 WTE) and a minimum 102 WTE Level 3/4 psychological practitioners.<sup>6</sup> Among those units who have psychologist input, staffing levels are lower than those recommended in the 2017 mapping exercise report with only 4 units meeting the 2002 renal psychology workforce requirement of 1.0 WTE per 600 RRT patients while five units have 1.0 WTE psychologist per <1,000 RRT patients.<sup>6</sup>

## Components of the role of adult psychologist

### Direct clinical work

#### Assessment

Renal psychologists offer specialist assessment considering biopsychosocial and treatment factors in the development and maintenance of presenting problems, working in inpatient and outpatient settings, with individuals and families.

A range of assessment methods are used, including:

- Interviews and direct observation;
- Psychometric tests;
- Neuropsychological assessment (health/counselling psychologists require further training to undertake this);
- Risk assessment and risk management plans;
- Assessment of mental capacity: particularly in relation to an individual's capacity to consent to medical treatment and to decide to withdraw from treatment;
- Assessing need for referral of patients to mental health services and/or other relevant agencies.

Following assessment, renal psychologists develop a formulation, drawing on psychological theory and research, making sense of the interplay between psychological and physical well-being, providing several hypotheses and treatment options. Where appropriate, this can be shared with the multi-professional team to facilitate collaborative working, consistent team approaches and increased understanding.

#### Transplant assessment

- Specific assessments such as recipient suitability for transplantation (required pre-transplant for all children and young people and for adults where risk factors for poor outcomes have been identified as per NICE RRT Guideline);<sup>22</sup>
- Formal mental health assessment for all non-directed altruistic donors as per British Transplant Society/Renal Association Guidelines;<sup>23</sup>
- Assessments of live related donors where clinically indicated.

#### Intervention

Based on the assessment, renal psychologists provide individually-tailored, evidence-based interventions/management plans using a range of approaches<sup>24-30</sup> including:

- Behavioural and cognitive behavioural techniques;
- Mindfulness;
- Compassion-Focused Therapy;
- Acceptance and Commitment Therapy;
- Motivational Interviewing;
- Family Therapy;
- Eye Movement Desensitisation and Reprocessing.

*Examples of interventions include:*

- Supporting adjustment to diagnosis, management of distress and maximising quality of life;
- Helping patients cope with the challenges of treatment, e.g. anxiety about hospitals and/or invasive procedures, symptom-management techniques, improving engagement and adherence with complex treatment regimes, medication, dialysis, diet and fluid restrictions;
- Psychological intervention for difficulties such as anxiety, depression, trauma or body image issues, linked to CKD or treatment;
- Preparation and support for patients through transitions, e.g. child to adolescence to adult services, hospital to home, transition from one dialysis modality to another, transition to transplant and from transplant to dialysis;<sup>31</sup>
- Assisting patients and health care professionals in decision-making about treatment, including planning of palliative care, where appropriate;
- Intervention and support to those with identified psychological needs related to the transplantation process;
- Psychological support for living donors;
- Planned proactive/protocol-driven work based on preventing or reducing possible long-term sequelae of chronic kidney disease; treatment plans (e.g. dialysis and transplantation), monitoring outcomes and effects;
- Group-based interventions.

*Patient education*

- Co-facilitate group patient education sessions or support other professionals in the development of the content;
- Assist with the development of written patient information.

Within their training, clinical psychologists specifically have experience and competencies of working across the lifespan, including people with learning disabilities and cognitive impairment. These skills can be applied in supporting the team where individuals in these groups require education.

*Consultation and joint working*

Renal psychologists can provide specialist psychological advice and guidance to renal unit multi-professional teams through:

- Consultation (e.g. at ward rounds, renal clinical and MPT meetings);
- Planned joint patient work with other MPT professionals;
- Clinical supervision (1:1 or group) to other renal team professionals;
- Providing staff support and reflective practice opportunities on an on-going basis and in response to specific, difficult situations. This work helps to manage and reduce staff stress and promotes effective communication and teamwork amongst colleagues.

*Education and support for renal staff*

Renal psychologists support the development of psychological skills and competencies within the renal unit staff team via:

- Teaching, training, consultation, education, reflective practice groups and supervision;
- Supporting front-line clinicians in their role (via supervision and overseeing direct work), to deliver routine psychological care using appropriate strategies for managing common psychological difficulties.

*Audit, research, service evaluation, and service and policy development*

As scientist practitioners, this area is a core role in practitioner psychologist job descriptions. The renal psychologist has specialist skills and experience in conducting psychological research. This is applied to understanding psychosocial issues in renal disease and improving psychological care in renal services through developing individual projects or advising on/participating in research carried out by the MPT.

The renal psychologist also brings specialist skills and experience in:

- Service evaluation;
- Audit and service development;
- Ensuring evidence-based and developmentally appropriate psychological approaches are embedded within policies, procedures and pathways in the renal unit (e.g. consent to treatment, transition from paediatric to adult services, managing distressing behaviour, procedural anxiety and education and preparation for dialysis and surgery including transplantation).

*Supervision/continuing professional development*

Renal psychologists have a responsibility to engage in continuing professional development (CPD) and supervision of their practice to maintain their Health and Care Professions Council (HCPC) registration. The amount of supervision will vary depending on the grade of a particular psychologist, however, this should be at a minimum of one hour per month for more senior staff, with increased frequency for those newly qualified.<sup>32</sup>

## 5.3 PAEDIATRIC PSYCHOLOGIST

### Components of the role of paediatric renal psychologist

Children and young people who are seen within specialist paediatric renal teams experience high levels of psychological distress and vulnerability. Children receiving dialysis have lower quality of life than their peers and are more likely to experience psychiatric conditions such as depression, anxiety and adjustment disorder.<sup>33,34</sup> Paediatric clinical psychologists aim to reduce psychological distress, promote optimal development and improve health outcomes including psychological well-being, by the systematic application of knowledge derived from psychological theory and data.<sup>15,34</sup>

Paediatric renal psychologists working within specialist paediatric renal teams help children, young people and their carers to:

- Develop the necessary skills and abilities to cope with their emotional needs and daily lives;
- Maximise their psychological and physical well-being whilst adapting to the impact of kidney disease;
- Develop and use their capacity to make informed choices about treatment options;
- Maximise developmentally appropriate independence and autonomy;
- Have a sense of self-understanding, self-respect and self-worth;
- Be able to enjoy good social and personal relationships and share valued social and environmental facilities.<sup>35</sup>

Paediatric renal psychologists also

- Treat the emotional and psychological impact of kidney disease;
- Support concordance with treatment plans;
- Ameliorate distress in relation to medical assessment and management.

The paediatric renal psychologist's role is also to support treatment decisions by ensuring that children and young people's care plans take account of the broader psychosocial context and individual factors such as resilience and emotional/psychological needs. It is vital that renal paediatric psychologists are embedded within the renal team so that children and families can receive co-ordinated interdisciplinary care. The key roles and components of the paediatric renal psychology service are similar to adult renal psychology, which are outlined in detail on page 41-42.

### Career pathway

Paediatric renal psychologists must be registered with and regulated by the HCCP as a 'practitioner psychologist' which may include clinical, health or counselling psychologist.<sup>36</sup> Currently, only clinical psychologists work within paediatric renal settings, predominantly because counselling and health psychologist training does not have to include a paediatric placement. Paediatric renal psychologists have an extended training (a minimum of 6 years) to doctoral level, prior to registration.

Paediatric renal psychologist's undergraduate psychology degree provides theoretical knowledge in psychological models and research methodologies based on an understanding of normal child development. As part of clinical psychology doctorate training, they will have gained clinical experience of working in a variety of interdisciplinary settings with a range of different patient groups and presenting problems, including working with children/young people, adults, older adults and people with learning disabilities.

Given that paediatric renal psychologists work with children and young people as well as their siblings and carers they learn to apply evidence-based practice across the lifespan, to be proficient in complex assessment, using a variety of psychological techniques at an individual, group and systemic level. Along with research methodology paediatric renal psychologists possess the necessary skills to work with complex psychological difficulties, including co-morbid physical and mental health problems, drawing on a range of evidence-based therapeutic treatment approaches. They provide supervision, and work in teams conducting research, audit and service evaluations, supporting service and organisational development.

### Continuing professional development

Paediatric renal psychologists have a responsibility to engage in CPD and supervision of their practice to maintain their professional HCPC registration.<sup>36</sup> They are responsible for keeping themselves up to date with knowledge of medical and physical aspects of renal disease as well as those relating to mental health. All renal psychological practitioners should be a member of either the Renal Psychologists Network Group or the RPT (Renal Psychological Therapists) group.<sup>37,38</sup> CPD is maintained through regular attendance at study days and meetings such as national and international renal, transplant or psychology conferences to maintain knowledge and awareness of scientific developments.

Clinical supervision is required to maintain clinical governance and quality and safety of patient care. The amount of supervision varies depending on the grade of the psychologist post. A minimum one hour per month for more senior staff is required, with increased frequency for those at newly qualified bands.<sup>32</sup>

### Proposed staffing levels

A comparison between the British Renal Society 2002 renal workforce plan<sup>21</sup> and a recent mapping exercise of the UK Renal Psychosocial Workforce revealed that marked variation in the provision of psychological resources to paediatric renal units remains.<sup>6</sup> The number and WTE of psychosocial staff working in UK paediatric units in 2017 are outlined in Table 1.<sup>6</sup>

TABLE 1. NUMBER AND WTE OF PSYCHOSOCIAL STAFF WORKING IN UK PAEDIATRIC UNITS IN 2017.<sup>6</sup>

Profession	Number of staff	Whole Time Equivalent (WTE)
Psychologist	14	5.7
Social worker	10	7.4
Play therapist	2	2
Counsellor/psychotherapist	1	0.5
Music therapist	1	0.2
Youth worker	1	0.25
Play worker (unqualified)	2	2

The UK renal psychosocial workforce mapping exercise identified that psychological services are primarily provided by clinical psychologists in paediatric services.<sup>6</sup> In addition, social workers, play specialists, youth workers/young adult workers, teachers and nurses also contribute to the psychosocial support and management of children and their carers. However, it is evident that there remains a significant variation in service provision nationally, which has led to a crisis intervention model of care in many units, rather than the proactive, integrated involvement of clinical psychologists as part of the MPT.

Within paediatrics, the suggested workforce recommendations is 1.0 WTE psychologist per 150 paediatric renal patients seen by a specialist paediatric renal service, based upon data from the UK renal psychosocial workforce mapping exercise, and recommendations from CF services.<sup>6,9</sup>

## 5.4 ADULT COUNSELLORS AND PSYCHOTHERAPISTS

### Introduction

Data from the UK psychosocial mapping exercise indicates that a total of 29 recorded counsellors & psychotherapists are working in 17 of the 84 renal units across the UK – this is representative of 16% of the total renal psychosocial practitioners working in the NHS.<sup>6</sup>

Table 2 outlines the components of the counsellors and psychotherapist roles. For inpatient referrals we suggest practitioners aim to see all inpatient referrals for specialist psychological input within 1 week. Clients with AKI are a separate group that benefit from early intervention.<sup>35</sup> We recommend outpatient referrals are seen within 2-8 weeks for either assessment and/or initiation of therapy, as a gold standard.

Although training routes are different for clinical psychologists and psychotherapists, the levels of knowledge required are equivalent, therefore psychotherapist jobs may be matched to clinical psychology profiles on an equivalent basis when banding job descriptions as documented on NHS employers.<sup>39</sup> As psychological practitioner roles (levels 3 & 4) are similar, counsellors and psychotherapists would align themselves with psychologists working in the NHS regarding proposed staffing levels – minimum and gold standard.

TABLE 2. COMPONENTS OF THE COUNSELLOR/PSYCHOTHERAPIST ROLE.

<b>Direct clinical work</b>
<p><b>Assessment</b></p> <ul style="list-style-type: none"> <li>• Use knowledge and skills to provide specialist assessments for patients, parents and carers/relatives</li> <li>• Clinical responsibility following assessment is to ensure that clients are referred to appropriate services when risks are identified e.g. mental health services, liaison psychiatry, safeguarding teams, social services or GP</li> </ul> <p><b>Transplant assessment</b></p> <ul style="list-style-type: none"> <li>• Provide specialist psychological assessments of donors, altruistic donors and recipients prior to surgery<sup>22,23</sup></li> <li>• Report-writing regarding appropriateness of donation to the MPT</li> <li>• Contracting for counselling as required post assessment</li> </ul> <p><b>Bariatric surgery assessment</b></p> <ul style="list-style-type: none"> <li>• All renal bariatric surgery candidates prior to planned surgery planning</li> <li>• Assessment report fed-back to the Bariatric MPT<sup>41</sup></li> <li>• Engaging and contracting for counselling may also be initiated following assessment</li> </ul> <p><b>Intervention</b></p> <ul style="list-style-type: none"> <li>• Short, medium or long-term counselling or psychotherapy using a range of evidenced based interventions/approaches tailored to the individual<sup>24,28,30</sup></li> <li>• Delivery of information/psycho-education; advocating and signposting to individuals, couples, families, carers and groups.</li> <li>• Use of Psychometric outcome measures</li> <li>• Preparation of young people transitioning from child health to adult services, as well as supporting existing young people with CKD and AKI within the adult service<sup>31</sup></li> <li>• Providing appropriate therapeutic interventions to support the potential donor or recipient, including post-surgery recipient adjusting to life with a transplant</li> <li>• Inpatient referrals</li> <li>• Outpatient referrals</li> </ul>
<b>Patient Education</b>
<ul style="list-style-type: none"> <li>• Provision of age-appropriate information for children or young people regarding CKD</li> <li>• Deliver pre-dialysis/transplantation educational seminars, individual or group psycho-education</li> <li>• Provide advice and support that is sensitive to the psychological needs of the patient, young person or family</li> <li>• Facilitate/co-facilitate support groups for renal patients and their families</li> </ul>
<b>Consultation and joint work</b>
<ul style="list-style-type: none"> <li>• Service development, ensuring equitable service offered across entire renal patient pathway, informed by patient experience</li> <li>• Contribute to MPT meetings/ward rounds</li> <li>• Liaise with social services, schools/colleges/community agencies for psychological/social input</li> </ul>
<b>Education and support for renal staff</b>
<ul style="list-style-type: none"> <li>• Participation and delivery of training on psychological impact of CKD</li> <li>• Support staff to manage anxiety and pain for patients receiving dialysis</li> <li>• Emotional containment – clients and staff</li> <li>• Provide clinical crisis support – debriefing sessions</li> <li>• Supervision for other healthcare professionals</li> <li>• Reflective practice groups, education, training and consultancy</li> </ul>
<b>Audit, research, service evaluation, and service and policy development</b>
<ul style="list-style-type: none"> <li>• Provide yearly audit updates and undertaking patient experience surveys</li> <li>• Contribute to research in all areas of renal health, developing individual projects or participating in research carried out by the MPT</li> </ul>
<b>Supervision</b>
<ul style="list-style-type: none"> <li>• Recommended minimum criteria: 1.5 hours/month for individual and double for group supervision. – ratio of 1:6 individual supervision hours to overall client hours<sup>42,43</sup></li> <li>• Practitioners supervising students or colleagues, within the team, require additional supervision time</li> <li>• An essential element of the job description funded by the trust/employer and delivered in work time</li> </ul>

## 5.5 ADULT SOCIAL WORKERS

### Introduction

Renal social workers across the United Kingdom work to 'promote social change and development, social cohesion and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing'.<sup>40</sup> Renal social workers work holistically to improve the wellbeing of people living with kidney disease; alongside their families and carers, from diagnosis to the end of life, in collaboration with other members of the multi-professional team. Throughout the patient journey they are the primary point of contact for practical and social care issues.<sup>44</sup> In addition, they aim to improve patients' experience of the wider systems through research, development and advocacy.

The commissioning and funding arrangements for renal social work services across the UK vary significantly, with posts being funded through: acute hospital services, local authorities or jointly funded between trusts and social services, or in some cases, charities.<sup>6</sup> The components of adult renal social work roles are outlined in Table 3. These vary depending on whether the worker has statutory duties, specifically under the Care Act 2014 and the Mental Capacity Act 2005 (England and Wales) or the Adults with Incapacity (Scotland) Act 2000.

### Career pathway guide

Social worker is a protected title, and each social worker is registered with a governing body; the Scottish Social Services Council; the Northern Ireland Social Care Council, Social Care Wales, or Social Work England.

To qualify as a social worker, a BA, BSc, MA or MSc in Social Work is required.<sup>49</sup> As standard practice, a social worker with a minimum of 2 years, post-qualifying experience is needed due to the complexity of kidney care. The equivalent level on the Skills for Care Career Framework is 6-7.

### Proposed staffing levels

If recommendations for psychosocial provision for CF services are applied, no renal units currently meet the gold standard social work recommendations of 1.0 WTE social worker per 150 renal patients.<sup>9</sup> The minimum standard for social work provision amongst CF patients is 1.0 WTE social worker per 140 patients. Within renal services in 2017, there were 58 social workers in adult units with a total WTE of 44.6 social workers in post at the time of the review.<sup>6</sup>

## 5.6 PAEDIATRIC SOCIAL WORK

### Introduction

Paediatric renal social workers respond to the psychosocial aspects of care relating to children with kidney problems, their carers' and family members.<sup>50</sup> Their role is to provide practical and emotional support to children (0-18 years of age) and their families to ensure they are able to effectively engage with, and consequently benefit from treatment for their kidney disease. Each paediatric renal unit is unique, requiring the social worker to be flexible and adaptable in their approach, individualising support to whomever they are working with. The paediatric renal social worker is a skilled and experienced practitioner who can offer tailored advice and support using an early intervention model to reduce the risk of situations progressing to crisis point.<sup>51</sup>

The bio-psychosocial model outlined by Beder (2006)<sup>52</sup>, is a theoretical model which demonstrates that the paediatric renal social worker works with the patient themselves, their family (including parents, carers and siblings) and their social and environmental contexts to address any factors which are negatively affecting their wellbeing. Paediatric renal social workers work holistically and may provide support that does not directly focus on the child, but helps improve their situation.

### Components of paediatric social work

Paediatric renal social workers undertake comprehensive psychosocial assessments of need with children and their parents, carers and siblings, which contribute to person-centred care planning.<sup>50</sup>

TABLE 3. COMPONENTS OF THE ADULT RENAL SOCIAL WORK ROLE.

General overview
<ul style="list-style-type: none"> <li>• To be an expert resource, providing specialist advice, information and support to adults with renal conditions, carers and health professionals, in relation to their psychosocial support needs</li> <li>• Make effective use of learning opportunities and evaluate and reflect on own knowledge/practice</li> <li>• Contribute to the learning and development culture within the renal unit</li> <li>• Build good relationships with renal patients and their carers, offering support that is holistic, proactive, and tailored to individual need</li> <li>• Promote equality, diversity and rights</li> <li>• Interpret the rights and responsibilities of people in a way that is consistent with the governing body's Professional Standards and British Association of Social Workers' Code of Ethics<sup>45,46</sup></li> <li>• Act in a way that acknowledges people's rights to make their own decisions and recognises their responsibilities, understanding the resultant dilemmas and developing appropriate solutions</li> <li>• Support anti-discriminatory practice and proactively identify and take action to address discrimination and oppression in self and others</li> </ul>
Tasks
<ul style="list-style-type: none"> <li>• Assessment of need</li> <li>• Carer support</li> <li>• Welfare rights and debt support</li> <li>• Applications to grant bodies on behalf of patients and families</li> <li>• Advocacy</li> <li>• Facilitating patient groups and forums</li> <li>• End of life support and advance care planning</li> <li>• Bereavement and pre-bereavement support</li> <li>• Transitions work for young people moving to adult services</li> <li>• Material help</li> <li>• The use of counselling skills to engage and support patients and families from all backgrounds</li> <li>• Support with housing issues</li> <li>• Employment issues</li> <li>• Completing Continuing Health Care paperwork in partnership with nursing colleagues and families</li> <li>• Family support</li> <li>• Promoting inclusion</li> <li>• Hospital discharge</li> <li>• Mental Capacity Assessment</li> <li>• Carer assessment</li> <li>• Safeguarding</li> <li>• Engaging with those who are hard to reach through a traditional medical model, e.g. focusing on the social reasons for non-adherence<sup>47</sup></li> <li>• Referrals to community specialist teams</li> <li>• Referrals for aids and adaptations</li> <li>• Immigration matters</li> <li>• Travel support</li> </ul>
Research and audit
<ul style="list-style-type: none"> <li>• Commitment for renal social workers to initiate and participate in multi-professional research/audit projects</li> <li>• Participate in local, national and international dissemination of research</li> </ul>
Education
<ul style="list-style-type: none"> <li>• Develop tools to support patients of all backgrounds – cultural, social, and educational – to understand their condition</li> <li>• Contribute to the multi-professional approach to pre-dialysis education</li> <li>• Formulate and implement bespoke in-house educational sessions to address identified needs</li> <li>• Support the learning needs of colleagues</li> <li>• Contribute towards the development and updating of information for renal patients, their families and carers regarding services and support networks</li> <li>• Attend relevant study days and educational programmes</li> <li>• Attend and participate in clinical and audit meetings</li> <li>• Support social work students undertaking placements in the renal service</li> </ul>
Service development
<ul style="list-style-type: none"> <li>• Work creatively within the MPT, using local and national evidence to promote enhanced ways of working</li> <li>• In partnership with the MPT, review service needs through audit, research, observation and peer review</li> <li>• Make recommendations on change and support the implementation and evaluation of new working practices using evidence-based practice</li> </ul>
Continuing professional development
<ul style="list-style-type: none"> <li>• All social workers must adhere to the standards of conduct, performance and ethics of their governing body in order to maintain their registration, including engaging in appropriate CPD</li> <li>• Renal social workers can be members of the British Association of Social Workers' Renal Special Interest Group<sup>48</sup></li> <li>• Social workers should commit to engaging in monthly clinical supervision</li> </ul>

The support provided will vary, in response to individual need. Support can include:

- Attending ward rounds, psychosocial meetings, multi-disciplinary meetings, assisting with complex discharge planning;
- Seeing patients, in outpatient clinics, dialysis units, in the community;
- Participating in shared decision making in preparation for dialysis or transplantation;
- Supporting siblings and family members;
- Liaising with the local authority in respect of safeguarding issues, contributing to chronologies, child protection plans and attendance of child protection conferences, core groups and strategy meetings;
- Conflict resolution/mediation between medical team and families;
- Safeguarding: dealing with initial disclosures; making referrals; participating in strategy meetings; Child Protection Conferences; core group meetings and care team meetings; liaising with hospital safeguarding teams; advocacy for the child and family;
- Dealing with specialist needs e.g. Learning disabilities of child and/or parents; communication needs e.g. non-English speaking; limited reading abilities; mental health issues; substance misuse;
- Support with immigration issues, letters for employment, benefits, housing;
- Accessing care packages, either from children's social care or children's continuing care;
- Early help plans, and acting as lead professionals;
- Transition support;
- End-of-Life Care and bereavement support;
- Facilitating groups and coffee mornings, e.g. dialysis families weekly support groups;
- Helping with benefits and charity applications;
- Support MPT members as they provide psychosocial support;

### Career pathway guide

Social workers in Britain have generic training which enables them to work with both adults and children, and they can then choose to specialise after qualifying. Paediatric renal social workers must have a recognised social work qualification and be registered with the appropriate regulatory body for the part of the UK in which they practise (regulation of social work is devolved to the regional governments within the UK).<sup>53</sup> Paediatric renal social work is a specialist post, and the standard practice would be to recruit a social worker with a minimum of 2 years post-qualifying experience. As with adult renal social workers, there are several ways in which paediatric renal social workers may be funded and employed. The job description will define the banding if employed under agenda for change.<sup>54</sup> Paediatric renal social workers must engage in continuing professional development in order to maintain their registration. They are strongly encouraged to become members of the BASW Renal Social Work Group, and maintain regular contact with the other paediatric renal social workers for peer supervision.

### Proposed staffing Levels

A work-force mapping exercise in 2018 revealed 10 paediatric renal social workers in the UK, of which 7.4 were WTE.<sup>6</sup> This is a reduction from 10.4 WTE documented in 2002.<sup>21</sup> There is very little research focusing on paediatric renal social workers, therefore evidence from other equivalent long term health conditions (CF) have been used for bench-marking. The Cystic Fibrosis Trust<sup>9</sup> recommendations are 1.0 WTE per 150 patients.

It is important that the paediatric renal social worker is embedded within the renal MPT to allow them to provide the necessary specialist support and advice. To achieve this, it is necessary for them to have sufficient time each week to both support families and to establish good working relationships with the other members of the MPT. This balance should be considered when factoring minimum staffing levels: a role with less than 0.5 WTE would make it difficult to achieve this balance.

Access to specialist paediatric renal social work is becoming more important as the thresholds for support from children's social care are becoming more focused on crisis management and responding to significant child protection concerns. Most children living with kidney disease and their families are not be eligible for support from community-based social workers.

TABLE 4. SKILLS FOR HEALTH CAREER FRAMEWORK FOR ADULT AND PAEDIATRIC PSYCHOSOCIAL PRACTITIONERS: PSYCHOLOGISTS, COUNSELLORS, PSYCHOTHERAPISTS, SOCIAL WORKERS.<sup>55</sup>

Level	Explanation	Psychologist	Counsellor/psychotherapist	Social worker
8	<ul style="list-style-type: none"> <li>Require highly specialised knowledge, some of which is at the forefront of knowledge in a field of work</li> <li>Leaders with considerable responsibility, and the ability to research and analyse complex processes</li> <li>Have responsibility for service improvement or development</li> <li>May have considerable clinical and/or management responsibilities, be accountable for service delivery or have a leading education or commissioning role</li> </ul>	<p><b>Consultant clinical/health/counselling psychologist</b>                      Provision of professional leadership and management of renal psychological services including:</p> <ul style="list-style-type: none"> <li>Leading on strategy, policy and service development</li> <li>Managing resources &amp; budgets</li> <li>Recruiting and managing renal psychology services staff</li> </ul> <p>These roles also retain significant components of providing direct clinical work, consultation, supervision, teaching/training and research (as detailed in Levels 6 and 7 below)</p>	<p><b>Consultant renal psychotherapist/counsellor manager</b>                      Renal specific skills include:</p> <ul style="list-style-type: none"> <li>Leading a specialist renal therapies team including line management &amp; providing supervision</li> <li>Budget management</li> <li>Knowledge of all aspects of the renal patient pathway and an understanding of renal diseases</li> <li>Ability to differentiate between physical and psychological symptoms</li> <li>Overall risk management responsibility</li> <li>Leading renal psychology/therapy research and carrying out complex service audits</li> <li>Leading service development, improvement &amp; education locally and nationally</li> <li>Involvement in Renal Policy development and commissioning</li> </ul>	
7	<ul style="list-style-type: none"> <li>Have a critical awareness of knowledge issues in the field and at the interface between different fields</li> <li>They are innovative and have a responsibility for developing and changing practice and/or services in a complex and unpredictable environment</li> </ul>	<p><b>Principal clinical/health/counselling psychologist</b>                      Skills include:</p> <ul style="list-style-type: none"> <li>Increased role in the leadership, organisation and management of the renal psychology service</li> <li>Increased managerial role and responsibility for others within the psychological service</li> </ul> <p><b>Senior/highly specialist renal clinical psychologist</b>                      Skills include:</p> <ul style="list-style-type: none"> <li>Leading service development</li> <li>Managing assistant and graduate psychologists</li> <li>Advanced clinical supervision skills enabling provision of clinical supervision to other qualified clinical psychologists and psychology service staff at senior/highly specialist level and below</li> </ul>	<p><b>Specialist or renal counselling manager</b>                      Skills include:</p> <ul style="list-style-type: none"> <li>Leading a specialist renal therapeutic team, including line management and supervision</li> <li>Overseeing the running of support groups, young people or transition clinics and end of life care</li> <li>Education and training – in-house and locally</li> <li>Renal service development and policy making (in-house)</li> <li>Renal research, audit, client questionnaires</li> <li>Risk management, including signposting</li> </ul>	<p><b>Team leader</b></p> <ul style="list-style-type: none"> <li>Responsibility for supervising renal social workers</li> <li>Attendance at management meetings</li> </ul>
6	<ul style="list-style-type: none"> <li>Require a critical understanding of detailed theoretical and practical knowledge</li> <li>Specialists and/or have management and leadership responsibilities</li> <li>Demonstrate initiative and are creative in finding solutions to problems</li> <li>Some responsibility for team performance and service development and they consistently undertake self-development</li> </ul>	<p><b>Equivalent of clinical/health/counselling psychologist</b>                      Skills include:</p> <ul style="list-style-type: none"> <li>Providing evidence-based assessment, formulation and psychological intervention to individuals and group interventions</li> <li>Specialist psychological assessment for transplant and live donation</li> <li>Risk assessment /management plans for individuals particularly in relation to deliberate self-harm</li> <li>Highly developed skills in providing specialist advice, consultation, teaching/training and supervision to wider renal team</li> <li>Post-doctoral level research, audit and service evaluation skills</li> <li>Contributing to service development</li> </ul>	<p><b>Specialist renal counsellor</b>                      Skills include:</p> <ul style="list-style-type: none"> <li>Acquiring specialist knowledge of renal patient pathway</li> <li>Working towards accreditation</li> <li>Supervision of trainee counsellors</li> <li>Running support groups; transition and end of life care clinics</li> <li>Involved in renal research, audit and service evaluation</li> </ul>	<p><b>Renal social worker</b></p> <ul style="list-style-type: none"> <li>Acquiring specialist knowledge of issues affecting those with long-term conditions</li> <li>Carrying out complex assessments and statutory social work tasks e.g. safe-guarding, mental capacity assessments</li> <li>Carrying out research/audit presentations at local/national fora</li> <li>Engaging with MPT in delivering patient education</li> <li>Chairing relevant meetings</li> <li>Supervising student social workers</li> </ul>
5	<ul style="list-style-type: none"> <li>Have a comprehensive, specialised, factual and theoretical knowledge within a field of work and an awareness of the boundaries of that knowledge</li> <li>Can use knowledge to solve problems creatively, make judgments which require analysis and interpretation, and actively contribute to service and self- development. May have responsibility for supervision of staff or training</li> </ul>			
4	<ul style="list-style-type: none"> <li>Require factual and theoretical knowledge in broad contexts within a field of work. Work is guided by standard operating procedures, protocols or systems of work, but the worker makes judgements, plans activities, contributes to service development and demonstrates self-development</li> <li>May have responsibility for supervision of some staff</li> </ul>	<p><b>Assistant psychologist</b></p> <ul style="list-style-type: none"> <li>Assists a qualified renal psychologist to support individual and group interventions</li> <li>Assists research and audit activities</li> </ul>		<p><b>Renal social work assistant</b>                      Assisting with:</p> <ul style="list-style-type: none"> <li>Support to patients</li> <li>Running of patient and carer groups</li> <li>Gathering of information for audit/research</li> <li>Taking on a caseload of less complex work under the supervision of the renal social worker</li> </ul>

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