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Working as a Team



THE RENAL SOCIAL WORKER: AN ESSENTIAL TEAM MEMBER FOR GOOD RENAL CARE?

Renal services do not need renal social workers to keep patients alive. Nephrologists, transplant surgeons and renal nurses can manage that challenge without our involvement. So why are social workers attached to a renal service? Are they just an added extra – an upgrade in the service rather than an essential component of it?



Renal social workers are, I believe, essential to good multi-professional care of the renal patient and their family, and without them the patient is being offered a much poorer service.

As professionals who work with human beings and all their irrationalities, we know just how complex individuals are. We are not content just to be alive; we think about the future, we have emotions and feelings enmeshed in our ability to reason, and we carry with us moral and social conventions.

Social work recognises this humanity and brings with it skills to work within the renal team that are different but complementary to those offered by the “medical model” in the healthcare system. I do not wish to imply that the rest of the team are not taking into consideration the complexities of the human experience. However, the focus

of their work is, and should be, to keep the patient alive or to alleviate suffering by using their medical and nursing training. A good multi-professional renal team should use each individual’s expertise and the team’s united contribution to patient care will far exceed that which could be offered by any one professional, no matter how skilled.

In this article, I will look at what a renal social worker does and the context in which social work functions. I will go on to discuss renal social work provision or lack of provision, in the United Kingdom, using figures from the British Association of Social Workers Renal Special Interest Group audit in 2007. The emphasis is on adult renal care because that is the context in which I work.

WHAT DOES A RENAL SOCIAL WORKER DO?

The renal social worker works within the team of doctors, nurses, dietitians, pharmacists, counsellors and psychologists who are involved in caring for patients with kidney disease. Social workers work with patients before they come to dialysis, with those on dialysis or who are being managed conservatively, with patients who have had a transplant and with those at the end of their life.

We can give advice and support on a range of personal, emotional and practical matters, working with patients and their families at home, in the hospital or the renal unit.

Some of the areas of work include:

- Hospital discharge planning
- Finances and benefits
- Grants from charities
- Referral to occupational therapists for aids and adaptations
- Housing
- Assessment for help at home, meals on wheels, warden call and telecare systems
- Residential and nursing home placements

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- Holiday grants
- Work and further training
- Carers' assessment and support
- Liaison and advocacy
- Support for those facing the end of life, and bereavement care.

Meeting with patients and their families in their own home widens the perspective which the patient and the social worker can bring to the renal team's work. When talking about being ill, people often say that the hardest thing is the feeling of being out of control and without any power. By meeting in a home environment and listening to the patient's narrative, and that of those closest to them, we can help the patient with the journey through illness, empowering and enabling them to take an active role in planning and managing their care.

Renal social workers can act as advocates or translators for the patient and their family, and for the renal team. Human communication is such a complex and delicate phenomenon, and in busy clinics and wards it can be difficult to find the right words and non-verbal communication to convey what we hope to tell patients and their families, and for them to let us know their thoughts and feelings.

Julia Darling illustrates this idea beautifully at the opening of her poem *Too Heavy*,¹ as she complains about the words used by her doctor as she is facing advanced breast cancer.

"Dear Doctor,
I am writing to complain about these words
you have given me, that I carry in my bag
Lymphatic, nodal, progressive, metastatic
They must be made of lead. I haul them
everywhere.

I've cricked my neck, I'm bent
With the weight of them
Palliative, metabolic, recurrent

And when I get them out and put them on the table
They tick like bombs and overpower my own
Sweet tasting words
Orange, bus, coffee, June."

CONSERVATIVE MANAGEMENT OF KIDNEY DISEASE

Renal social work has much to contribute in the care and support offered by the renal team to patients undergoing conservative management, and their families. Social work can give time to the patient for discussions about living as well as

possible with kidney disease and about death and dying. Accessing community services to support patients in their own home as they become increasingly frail and supporting carers is central to social work.

The renal team needs to work together with primary care to ensure the best possible care for patients who are managed conservatively, and it is essential to make clear who is leading the management. The combination of the management of renal symptoms plus good psychosocial care with integral social work provision means that conservative care is a real treatment option and not simply choosing not to dialyse.

Social work can contribute greatly to the renal team's care as patients approach the end of their life if they are managed conservatively or withdraw from dialysis. Having time to talk about preferred place of death as early as possible can be invaluable. The social worker can liaise with community services, the hospice or nursing homes, to ensure that the patient receives the care they need in the place they wish to be.

WORKING WITH CARERS

Supporting people caring for renal patients is an important part of a renal social worker's workload. It is, in fact a duty, placed on local authorities under The Carers (Equal Opportunities) Act 2004² to inform carers of their right to a carer's assessment.

A carer's assessment will look at all the areas of a carer's life affected by the caring they take on, and will look at the help and support available to sustain them in this caring role. This could be emotional, practical or financial support. Many areas of the country have direct payment schemes for carers, whereby the carer can access money to spend on equipment or services that will help them to continue to care, such as a mobile phone, gym membership or driving lessons.

ARE THERE SOCIAL WORKERS WORKING IN ALL RENAL TEAMS IN THE UK?

The National Review,³ published in 1993, expressed great concern about the variation in renal social work provision across the UK. By 2001, the Kidney Alliance⁴ regarded renal social work as "one of the most under-resourced renal services".



The Renal National Service Framework (NSF) Part One (2004)⁵ and Part Two (2005)⁶ emphasised the importance of psychosocial care from a multi-professional team, but with little direct reference to the need for social work involvement to ensure that psychosocial care is delivered. Before the publication of the renal NSFs, the National Renal Workforce Planning Group published a recommendation⁷ that provided renal social work with an established position within the framework of services and offered clear targets, in terms of achieving workforce planning standards required to implement the NSFs.

The workforce planning group recommended that to provide an adequate renal social work service would require one whole-time equivalent post per 140 renal replacement therapy (RRT) patients.

In 2007, the Renal Social Work Special Interest Group undertook a second audit⁸ to establish the current workforce data and note any significant changes. Two hundred and fifty-five units were audited and 63 renal social work posts identified: 54 adult and 9 paediatric posts, with 52% being part-time. The audit examines the complex funding and contracting issues in detail. In adult renal services in the UK in 2007 there was one whole-time equivalent social worker to every 813 renal replacement therapy patients.

This number is a far cry from the one whole-time equivalent renal social work post for every 140 RRT patients recommended by the Renal Workforce Planning Group. The shortage of renal social work provision is, in fact, even more severe when the work undertaken with pre-dialysis and conservative care patients is taken into account.

At the core of these workforce problems lie the twin issues of lack of recognition of the important contribution of renal social work by some renal service providers and the continued lack of clear responsibility for funding this service.

SUMMING UP

This article illustrates some of what renal social workers can do for patients and their families. The challenge to renal services is how they can ensure that renal social work is a key part of their service. Without a renal social work service, patients and their families do not get the holistic, multidisciplinary care and support that the Renal NSF expects us to deliver.

The renal community should be aspiring to a future where every renal service throughout the UK can provide a multi-professional renal service, with integrated renal social work provision that works with the humanity of our patients as well as with their disease.

Case study: helping a patient nearing the end of life



Fred is an 83-year-old man with severe heart failure who has been admitted to hospital with increased shortness of breath, nausea and vomiting. He is diagnosed with end-stage renal disease and options for treatment are discussed with him, and with his wife and daughter. Everyone hopes Fred can get home as soon as possible and he requests that his renal disease is

managed conservatively, recognising that he is near the end of his life.

I co-ordinated Fred's discharge with his family, district nurses and the occupational therapist. I visited the family at home the following day and completed a carer's assessment and relevant benefits applications. Fred's condition stabilised unexpectedly over the next few weeks and he was managing, with a small care package, to live downstairs in his own home.

Fred's daughter had returned from living abroad the week before Fred's admission, and her home in the UK was a long distance away in Aberdeen. Once Fred seemed settled she was hoping to return to Aberdeen for a few days every two weeks. A carer's direct payment helped fund these journeys, sustaining Fred's daughter in her caring role.

The family were given written information about the management of renal symptoms and the support the renal team could offer, together with contact details.

Eight months later, Fred's daughter got back in touch with me as her father's condition had deteriorated again. This time, it looked as if he was nearing the end of his life. The renal physician liaised with the GP, and the district nurse and I worked together to increase the care package, through continuing healthcare funding with night sitters.

The family were feeling the strain of caring, and Fred's wife expressed her concerns about his deteriorating physical condition and how they would manage his dying at home. We discussed the option of hospice care, and Fred's name was put on the waiting list after his family visited the local hospice. Fred was admitted to the hospice a few weeks later and died peacefully four days after admission. I was then able to continue supporting the family following his death.

references

1. Darling J, Fuller C. *The Poetry Cure*. Bloodaxe, 2005.
2. The Carers (Equal Opportunities) Act 2004.
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4. The Kidney Alliance (2001) *End Stage Renal Failure – A Framework for Planning and Service Delivery*.
5. *National Service Framework for Renal Services Part One: Dialysis and Transplantation* (2004). Department of Health.
6. *National Service Framework for Renal Services Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life* (2005). Department of Health.
7. *The Renal Team – A Multi-Professional Renal Workforce Plan for Adults and Children with Renal Disease*. National Workforce Planning Group recommendations 2002.
8. British Association of Social Work Renal Special Interest Group (2007) *Renal Social Work Provision in the UK*.

Case study: helping a young renal patient



Jane was a 27-year-old woman who arrived into the care of Renal Services 20 weeks pregnant. She had recently moved to live with her sister and near to her parents who were hoping to support her through this pregnancy. Jane wanted to go ahead with the pregnancy, recognising that she would need to go onto dialysis and that going through with the pregnancy would mean that she would probably become dialysis dependent. Initially Jane needed a lot of social work input to help her find appropriate affordable

accommodation and sort out her complicated benefit claims, including a disability living allowance appeal. Jane lost her child and was devastated. At this time she was living with her parents and she did not feel emotionally well enough to live on her own. Jane attempted suicide but did not wish to meet with the Community Mental Health Team or our renal psychologist.

I continued to meet regularly with Jane and her mum and Jane was eventually offered suitable council accommodation. We applied for a community care grant and with the help of the British Kidney Patient Association and the Kidney Research UK, she furnished her new home. Slowly life was becoming more bearable and we organised a spa weekend funded from a Convalescent Trust.

Meanwhile plans were going ahead for Jane and a donor to be worked up for a live transplant operation. This hope of freedom from dialysis was dashed as the transplant could not proceed and Jane felt despairing again. Jane has her ups and downs, with vascular access being a major problem but we are working together to look at further training and employment, slowly taking each day as it comes, trying to find a life that is worth living. I have tried to walk along side Jane during the past 2 years offering my skills within a caring multi professional renal team, with dedicated doctors and nursing staff.

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