

# Developing and sustaining a renal supportive care service for people with end-stage kidney disease

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## Abstract

**Background** The poor, self-reported quality of life, high symptom burden and complex care needs of dialysis patients prompted the development of a renal supportive care service at St George Hospital.

**Aim** To report the development of a renal supportive care service at St George Hospital and methods used to sustain its growth.

**Method** Supportive care consists of outpatient and inpatient services with four specific groups of patients identified as the primary clientele. These groups are those on a conservative (non-dialysis) pathway, end-stage kidney disease (ESKD) patients with a symptom burden requiring specialised management, patients on dialysis considering dialysis withdrawal and ESKD patients with cancer. Services consist of complex symptom management, end-of-life (EOL) care and coordination of services to assist the patient to stay at home as long as they are able.

**Conclusion** The future of the supportive care service looks promising; therefore, it is important to incorporate this as part of routine patient care in ESKD. There is a need to pass on renal supportive care knowledge to the renal care teams to assist ESKD patients to live as well and as comfortably as possible, whether they choose a dialysis pathway or not, and to engage in clear conversations with patients and carers throughout the disease trajectory.

## Keywords

End-stage kidney disease, supportive care, palliative care, dialysis, renal.

## Introduction

There has been a considerable groundswell of interest from health professionals on the topic of renal supportive care of end-stage kidney disease (ESKD) patients in renal departments across Australia and New Zealand in recent years. That interest, and an awareness of the importance of supportive care in the ESKD population, has prompted the evolution of a successful renal supportive care service at St George Hospital in Kogarah, Australia. It has also prompted a high level of interest from other renal units in the methods used by St George to sustain the renal supportive care services development.

Supportive care has been defined by the National Council for Palliative Care in the United Kingdom (2011) as a holistic service which:

*... helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the*

*disease. It is given equal priority alongside diagnosis and treatment (The National Council for Palliative Care, 2011, p. 1).*

As the general population ages, decisions regarding whether or not to start dialysis become more complex. These decisions are not made lightly and should take into account patient and family wishes, medical history and comorbid disease burden. Patients on dialysis sometimes reach a point where decisions need to be made regarding the continuation of dialysis. This usually occurs after the occurrence of a sentinel event or a severe functional decline, where dialysis may no longer be providing benefit to the patient.

Patients who are on dialysis may experience a severe symptom burden which requires expert management. It is often unappreciated that this symptom burden can be as high as that of cancer patients (Weisbord *et al.*, 2003). Given that palliative care has this expertise, an alliance has been formed to manage the comfort of these patients in collaboration with the renal team.

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## Background

Since 2001, the renal unit at St George Hospital has measured the quality of life (QOL) of dialysis patients as part of its quality improvement programme using the Short Form 36 Health Survey (SF-36<sup>®</sup>) tool (Medical Outcomes Trust and QualityMetric Incorporated, 2003). We found that the QOL of dialysis patients remained persistently lower than that of the Australian normal population (Australian Bureau of Statistics, 1995; Population Research and Outcome Studies Unit, 2004) and has been very difficult to shift due to the many personal, social and environmental influences in a patient's life which converge and play a role in how a person rates their QOL (Wilson & Cleary, 1995).

There have been many changes in patient care since 2001 that could have, in theory, improved the patients' QOL, including improved monitoring and management of the dialysis patients' biochemical and haematological management; advances in dialysis technology over the years such as high-flux dialysers and changes in the composition of dialysate; improved nutritional status of patients and an intradialytic exercise programme for haemodialysis patients. All these have showed no significant improvements in the overall QOL (Figure 1) with one exception; an exercise study which improved physical function (Cheema *et al.*, 2007; Painter *et al.*, 2000) and vitality (Cheema *et al.*, 2007), both domains of the SF-36<sup>®</sup> survey for the participants.

The symptom burden of the St George hospital haemodialysis patients has been measured along with the QOL. Symptom burden was measured as part of a randomised control trial (RCT) in the haemodialysis unit using the Memorial Symptom Assessment Scale Short Form (MSAS-SF) (Portenoy *et al.*, 1994). A high percentage of patients were identified as suffering from

lack of energy, pain, lack of sleep and itching similar to those reported by Murtagh *et al.* (2007). The RCT was carried out with approval granted by South Eastern Sydney and Illawarra Area Health Service Human Research Ethics Committee – Southern Section (HREC) for both QOL measurement in the dialysis population and for the RCT. The RCT measured whether patients who had access to a palliative care consultation as part of their routine renal care had an improvement in QOL and symptom burden compared to those who didn't have a palliative care consultation. This research is currently being peer reviewed for publication.

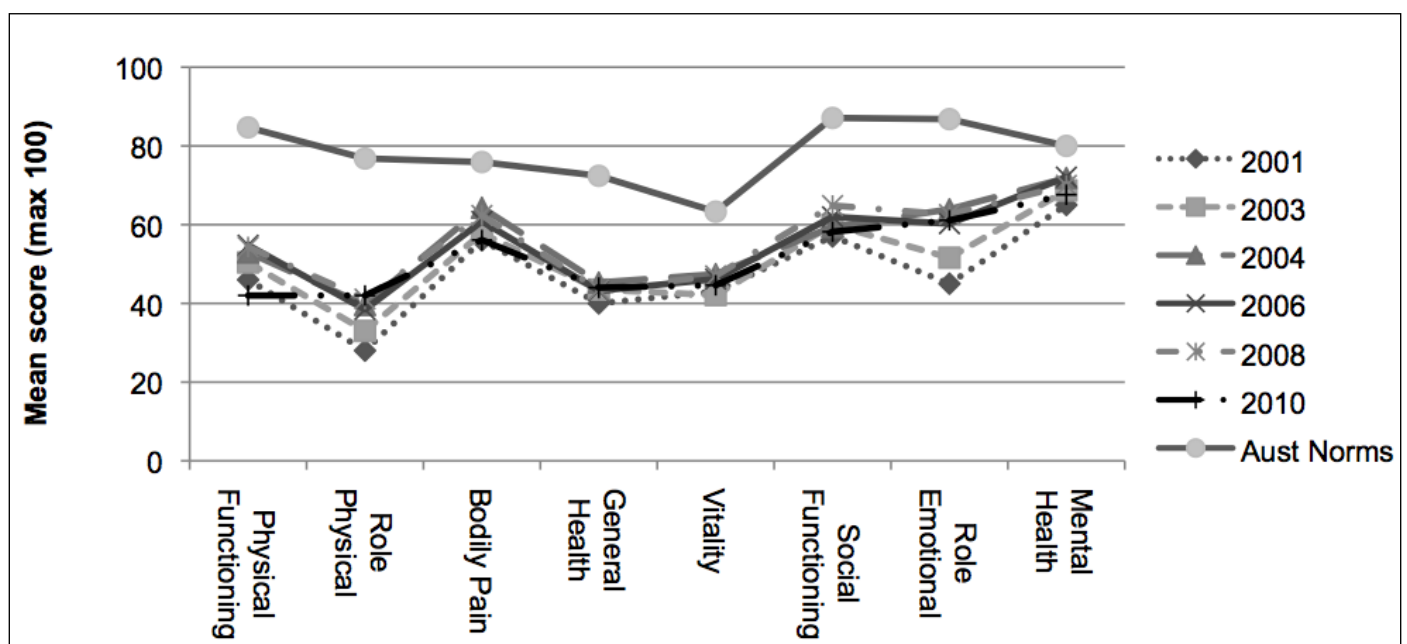
## Key stakeholders

Positive feedback from patients who had seen the palliative care consultant as part of the RCT was a good indication that a renal supportive care service could be incorporated into the ESKD care programme for both dialysis and conservatively managed patients to supplement their nephrology care.

A committee, comprising of the Director of Palliative Care, Director of Renal Services, a palliative care consultant, two renal clinical nurse consultants, a renal dietitian and a renal social worker, was formed before the renal supportive care service was established to discuss in detail how to collaborate to provide a quality, evidence-based supportive care service appropriate to ESKD patients. Guidelines for renal-appropriate symptom management medications and end-of-life (EOL) medications were developed by this committee to assist in symptom management and for teaching others.

Key stakeholders needed to be identified and processes for developing collaborations and clear methods of communication were required to minimise barriers to a successful service. Consideration as to what resources the renal supportive care

Figure 1. Mean QOL scores per year of survey.



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service would require to support patients was an important step. Although patients already have access to many services within the St George Hospital system, especially if undertaking dialysis, there needed to be clear methods to assist those on a conservative pathway who wanted to remain at home for as long as possible. The identified major stakeholders are ESKD patients and their significant others, the Area Health Service, renal physicians, palliative care health professionals, geriatricians, renal and palliative care nurses, social workers, dieticians, hospices, residential aged care facilities, community nurses, pharmacy and general practitioners. All of these stakeholders have a degree of influence on the renal supportive care service as a whole.

## Key components to the renal supportive care service

Fundamental to the success of the programme has been the cooperation that has developed between the renal service and the palliative care service, with access to a palliative care consultant who now spends time within the renal unit. The palliative care consultant works with the nephrologists to support the care of their patients, whether they are on dialysis, pre-dialysis or conservatively managed. It is important that nephrologists and patients understand that a palliative care physician is not a renal specialist and patients must continue to have access to expert renal care while participating in the renal supportive care service. Patients referred from the nephrologists are never 'handed over'. The nephrologist continues to provide "active disease management" while the palliative care physician acts in a supportive role (Murtagh, Marsh *et al.*, 2007, p. 1955). Together, the renal supportive care service and the nephrologists care for the patient right up to the EOL.

The renal supportive care service incorporates outpatient clinics, inpatient care and the development of renal supportive care guidelines such as renal appropriate symptom management (using medications where appropriate that are suitable in ESKD), and providing ongoing education to staff and others. Outpatient clinics are run weekly with a view to increasing with demand but are limited by clinic space. Outpatient clinics involve not only patient consultations, but assessing symptom burden, referrals to allied health and community organisations, coordinating urgent admissions and providing educational opportunities of other health professionals including trainees in renal medicine.

Inpatient services include managing new referrals of ESKD patients from nephrologists for symptom management, participation in family conferences, EOL care (palliative care and supportive care share this role), appropriate referrals to palliative care institutions (hospice), expert symptom management advice for staff caring for renal patients (especially if the patient is not admitted to a renal ward or is admitted under another speciality for another reason), and appropriate referrals to other specialities such as to the pain team. Patients that have been seen previously by the renal supportive care service as an outpatient are also followed up when they are admitted to hospital.

The clinical nurse consultant (CNC) visits inpatients regularly to monitor progress when there has been a change in symptom management medications, to monitor pain and to support the patient and their relatives. Patients that have pain that is not yet under control or other distressing symptoms such as delirium require frequent visits until symptoms are under control. Relatives often need reassurance too.

## Clinic clientele

Four main categories of patients are referred to the renal supportive care service (Table 1). First is the conservative (non-dialysis) patient group. These patients may be unsuitable for dialysis due to advanced dementia, or through discussions with their nephrologists and due to their clinical circumstances (usually advanced comorbid disease) have made a decision that dialysis will not be pursued. These patients continue to have their renal care managed by a nephrologist, but also see the palliative care consultant for symptom management and later for EOL care, including support for the family.

The second group are those patients who are either pre-dialysis (planning to have dialysis in the future) or current dialysis patients who have a symptom burden requiring more specialised management, that is, the patient reports their QOL is significantly impacted by a symptom such as pain or pruritis, which may cause a degree of suffering or distress for them and they need improved symptom control. These patients are referred by their nephrologist, or by nursing staff with the nephrologists' knowledge.

The third group are those who are considering withdrawal of dialysis. These patients come to the clinic, often with their 'significant other', to have a planned discussion regarding the patient's wishes for future care (Murtagh *et al.*, 2009). These discussions can occur over a number of clinic visits and require expert communication skills to uncover the whole patient story. The decision to withdraw from dialysis does not take place from the clinic alone, but rather after discussions with the patient, family and nephrologist; the final decision to withdraw from dialysis occurs with the nephrologist. Sometimes a psychological review is required to ensure there is not an element of depression or other mental illness driving the patient's decision. Following a final decision to withdraw from treatment, plans are made for care of the patient until death. These discussions commonly unfold following significant functional decline of the patient, where continued dialysis can be seen as futile or of no benefit to the patient.

Table 1. Four main categories of patients attending the renal supportive care clinic.

	Numbers	Percentage
Conservative care	70	57
Symptom management	35	29
Withdrawal of dialysis	7	6
Dual diagnosis	10	8
Total	122	100

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The last group seen in the clinic are patients who have a dual diagnosis of cancer and ESKD. These patients may have had a new cancer diagnosed while undergoing dialysis, or a recurrence of a past cancer. The renal supportive care service can start seeing these patients once the patient is no longer seeing the oncologist (the cancer therapy has finished, or they are now considered palliative care). Where active cancer treatment is occurring, it is more appropriate that the oncologist treating the patient manages the patient's cancer-related symptoms.

## Inpatient clientele

Inpatients are referred to the renal supportive care service through the renal team. These patients are usually referred for symptom management or as an introduction to the renal supportive care service if they are conservatively managed (a non-dialysis pathway). Conservatively managed patients do not always require symptom management straight away, so an early introduction to the renal supportive care service helps to lay a foundation for future visits, and potentially alleviates anxiety either when the patient is admitted for EOL care or requires symptom management in the renal supportive care clinic.

Referrals for EOL care occur in conjunction with the palliative care service. The patient is automatically referred to palliative care to ensure patients have the best opportunity for a 'good death' through expert shared care. It is important that at some later date we will be able to measure whether patients have a 'good death'; therefore, excellent record keeping is vital. Measuring a 'good death' is discussed by McAdoo *et al.* (2011) and incorporates many aspects integral to our renal supportive care service such as referral to palliative care at EOL, good symptom control and use of an EOL pathway. The St George Hospital End of Life Care Pathway has components incorporated into it which will enable future audits to take place to measure this.

Patients who are referred for symptom management sometimes have such complex pain that referral to the pain team is required. An example of this is calciphylaxis pain, which can be extremely difficult to manage and sudden escalations can occur without warning. Osteoarthritis and neuropathy pain are common comorbid conditions amongst the ESKD patients seen by the renal supportive care service at St George Hospital.

## Barriers

When the St George Hospital initially set up the new renal supportive care service, potential barriers were identified. One potential barrier identified during the RCT from the patients' point of view was a lack of understanding of the supportive role that the palliative care service plays within the nephrology service. Patients and carers often view 'palliative' as EOL care, not in a role that supports the patient through diagnosis, to treatment as per the National Council for Palliative care (2011) definition of supportive care. To overcome a barrier where the word 'palliative' can be seen in a negative light, the word 'supportive' was used instead. Supportive is a word that is all-encompassing of our aims for this clinic. The palliative care

physician plays a supportive role for the renal team with the aim to reduce the suffering of patients and make the transition from active care to EOL care smoother when that time comes.

Ineffective communication is another barrier as communication is of vital importance to both patients and family in end-stage disease (McAdoo *et al.*, 2011). It is important to avoid any discrepancy between what the patient and family understand regarding prognosis and what the physician is attempting to convey. Families sometimes do not engage or may have unrealistic expectations of a cure (Chambers & Brown, 2010). Clinic discussions cannot be rushed as time constraints can cause barriers to effective communication and patient care in this setting. A minimum of 30 minutes has been set for clinic consultations, but this can be pressed when the clinic is in high demand, running the risk of ineffective visits.

There needs to be a willingness of nephrologists and other physicians to discuss EOL decisions and advance care planning (ACP) with patients while they have the cognitive ability to decide what pathway they would like to proceed with. There is a recent comprehensive American guideline written by the Renal Physicians Association (2010) called *Shared decision making in the appropriate initiation of and withdrawal from dialysis*. The fundamentals of these guidelines appear to be transferable to the Australian health care network. This evidence-based guideline takes the reader through a series of 10 recommendations, including shared decision making regarding treatment choices, deciding whether to initiate or discontinue dialysis, circumstances where it is reasonable to consider forgoing dialysis, resolving conflicts about dialysis decisions, providing effective palliative care services to manage disease burden and clear communication strategies to ensure patients understand diagnosis and treatment options and goals of care. These recommendations are written as expert opinion from a Renal Physicians Association working group using evidence, literature, ethical principles and American statutory law (Renal Physicians Association, 2010).

Availability of palliative care specialists can be a barrier. At St George Hospital we have a specialist available and include renal supportive care education into the renal advanced trainee education programme. This will be discussed in more detail under the heading of sustainability.

## Role of the renal supportive care team

Inpatient and outpatient services are provided to ensure expert symptom management for ESKD patients and EOL care where required. Symptom management involves outpatient clinic visits by patients, while inpatient services involve consultations of new referrals and follow-up of existing clinic patients. The supportive care clinical nurse consultant is a 0.5 part-time position, which involves coordinating clinics, reviewing inpatients, receiving new referrals, referring patients to other services appropriately, discharge planning, family conferences, patient/family and staff education, facilitating admissions during outpatient clinics, monitoring inpatient medications for renal-appropriate dosing, phone calls to patients at home, managing data collection and



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participation in research. There is room to increase the position to include home visits. Once patients become housebound due to their deteriorating functional status, there is a much greater reliance on home services such as general practitioner home visits, community nursing and other services. Once the patient and/or family can no longer cope at home, it is likely that a nursing home will need to be considered (this is more appropriate for an elderly patient). If death is imminent and dying at home is not an option, then hospital care may be appropriate in cases where there is no hospice available.

EOL care at St George Hospital occurs with the involvement of the palliative care team to ensure the patients' needs are met. Referrals can be made to hospice facilities or, for those who wish to die at home, to community palliative care teams. This usually occurs during a hospital admission, but can occur by other means such as by phone when the patient does not want an admission. Referral to hospice can be facilitated by the renal supportive care nurse once a clear referral process has been established with the facility. It is important to have clear communication with the family prior to referral to hospice care, as some facilities may have strict time boundaries where, if the patient survives longer than expected, a discussion will occur regarding nursing home placement. The family needs to be aware of this to minimise distress.

### Measurement of outcomes

Renal supportive care clinic patient outcomes have been measured using the Patient Outcome Scale symptom module (renal version) (POS-S renal), the MSAS-SF, SF-36<sup>®</sup>, patient satisfaction and soon to be introduced family satisfaction surveys. Monthly statistics are collected to monitor the usage of the renal supportive care service for both inpatients and outpatients.

The MSAS-SF is used for symptom management purposes due to the reliability and validity shown when used with cancer patients (Murtagh & Weisbord, 2010; Weisbord *et al.*, 2003). It measures 32 common physical and psychological symptoms which are scored according to levels of distress or frequency for the psychological variables. It is used on the first visit and then six-monthly due to the length of the survey and the need to be mindful of not overburdening patients with surveys. It would be worthwhile validating this tool with the renal population.

The POS-S (renal) is used as a tool to monitor progress in individual symptoms and as a prompt in the clinic, so that no symptoms are missed during the patient's consultation with the doctor. It is a brief tool, primarily aimed at patients with advanced disease, where completing surveys would be quite difficult or even seen as a burden (Murtagh & Weisbord, 2010). It has worked successfully in the context of this clinic as patients and family (and clinicians) are not forgetting to mention specific problems, and the clinician can systematically go through the form with the patients, thus not missing troubling symptoms that the patient has identified.

Health-related QOL is measured using the SF-36<sup>®</sup> v2 Health Survey (Medical Outcomes Trust and QualityMetric Incorporated, 2003) which is used as part of standard practice for all renal replacement therapy patients at St George Hospital.

It has also been used successfully in the ESKD and chronic kidney disease (CKD) populations around the world (Finkelstein & Finkelstein, 2010; Finkelstein *et al.*, 2009). The SF-36<sup>®</sup> is given to the renal supportive care clinic patients at the initial visit and then six-monthly on a voluntary basis. Whether patients return these or not, again we are very mindful of overburdening patients with surveys.

Patient satisfaction is being measured using a non-validated tool to measure briefly whether their needs are met by the clinic. The same survey is used for the pre-dialysis patients who visit the pre-dialysis clinic. The reason a non-validated tool was used instead of the standard NSW Health outpatient survey tool is because the NSW Health tool is eight pages and 79 questions long (NSW Health, 2011) and we felt we would be asking too much from the patients in terms of surveys.

The arrangement between nephrology and palliative care is one of shared care, where patients are referred to palliative care once it is clear they have reached the EOL, or are referred to community palliative care service where there is a significant symptom burden and they are reaching the EOL or the patient wants to die at home. Even at this stage, clinic visits with their nephrologist are maintained if possible; many such patients have known their nephrologist for over a decade and these visits can offer further support.

According to the latest figures published by the Australian Institute of Health and Welfare (2011), national mortality data compared to Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) incident ESKD cases appears to indicate that the numbers of patients dying of ESKD without any renal replacement therapy (RRT) is almost equal to those registered on ANZDATA as undergoing RRT (10,4 vs 10,9 respectively) (Australian Institute of Health and Welfare, 2011, p. 8). Therefore, it appears there are many ESKD patients cared for in the community who are never initiated onto dialysis. This data does not indicate whether these patients have ever been referred to a nephrologist.

### Sustainability

Sustainability of the renal supportive care clinic lies in the tangible benefits for the patients, their carers, clinicians involved in their management and the availability of the palliative care physician. Those benefits will be quantified using the multiple tools of measurement of levels of symptom severity, QOL and patient satisfaction in addition to survivorship. Given that there are a limited number of palliative care physicians, one key aspect of sustainability is nurturing the knowledge base and skills in renal supportive care of health professionals working in nephrology. With this in mind, one aspect of the programme has been to embark on an extensive education of junior medical staff working in nephrology, including renal trainees and also through multiple formal talks given by the authors throughout Australia and New Zealand to nephrology, palliative care and general audiences.

### Advanced Care Planning

ACP aims to ensure that patients are given the opportunity to engage in an ongoing dialogue with their health care team in treatment decisions that may impact on their future care. The

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value of ACP is pinned by ethical principles of autonomy and client self-determination (Davison, 2009). Davison (2006, p. 886) also discusses how the ESKD patient's ability to maintain hope can be facilitated by an ACP if they can "imagine possibilities for a future that were consistent with their values and hopes". As illness progresses, Davison (2006, p. 889) emphasises that "health professionals, through ACP, play a critical part in reshaping what patients imagine for their future and what they hope for".

In the context of renal supportive care, the significant clinical advantage of ACP is that a competent patient can identify their person responsible, clarify their preferences and develop individual plans for future care. In engaging in such an ongoing dialogue, it is expected that this process will only strengthen and enhance shared decision making among patient, person responsible and the nephrology health team. The ACP could then be helpful to family and health care providers in making medical decisions.

Ideally, ACP would form a routine part of care in nephrology, especially for those patients with a poor prognosis, multiple comorbidities, chronic poor nutritional status and/or a poor performance status; for example, if the patient has a high symptom burden and can no longer manage all their own activities of daily living. There is limited international literature available describing the uptake of advance care directives in nephrology. Barriers exist from the perspectives of both patients and clinicians; these are listed by Davison (2009, p. 171). Patient-related barriers include lack of knowledge of what an ACP is or how to complete one, fear that the ACP won't be followed, reluctance to talk about death, assumptions that the family/carer already know what they want, and changing their mind on what they want. Health professional barriers include lack of training in ACP, lack of familiarity with what conservative care means, fear of the ACP discussion, fear that discussing EOL will destroy hope, clinic time constraints, and leaving it too late (the patient now not capable to make decisions). Furthermore, despite a reluctance of nephrologists to initiate in EOL discussions, many patients welcome the opportunity and look to their nephrologist to engage in these discussions. A departmental policy is being developed that involves initially one-to-one discussions between nephrologists and the palliative care physician to address barriers and general perspectives around this sometimes difficult subject.

## Discussion

An important aspect of any renal supportive care service is structure and framework. This should be determined by an overriding philosophy of care. The philosophy that has driven this service has been an emphasis on a model of shared care (where both standard nephrology care and renal supportive care has occurred concurrently) and continuity of care. The latter emerges from recognition that all patients, whether on a dialysis or a conservative pathway, will have highly individual and varying needs. In addition, the needs expressed are usually multifactorial and indeed complex. Those needs may be determined, at least in part, on the trajectory of their illness. From its inception, the renal supportive care team has seen it crucial to be able to respond to those shifting and varying needs both flexibly and expeditiously.

Supportive care in nephrology is well established in the United Kingdom as seen by the comprehensive documents and books published such as *Supportive Care for the Renal Patient*, the *Liverpool Care Pathway for the dying patient* and *The National Framework for Renal Services* (Chambers *et al.*, 2010; DH Renal NSF Team, 2005; DH Renal NSF Team and Marie Curie Palliative Care Institute, 2008). Supportive care should be incorporated into all ESKD patients' treatment pathway as part of routine care. It is more likely that patients with a high comorbid disease burden or the elderly will need to access supportive care services, but symptom management needs to cover all ages. Currently the renal supportive care services at the St George Hospital include an outpatient clinic, inpatient services, social work support, dietician support and links with the local hospice. There is room for expansion where home visits could assist those who can no longer make the trip into the hospital.

## Conclusion

The future of the renal supportive care service in Australia is promising; there is already a great deal of enthusiasm in many renal units to adopt a similar model of care, including rural outreach services. A major barrier to progress is the lack of palliative care specialists; it is, therefore, imperative that current advanced trainees in renal medicine are well trained in the principles of renal supportive care so that the patients can live as well as possible throughout the trajectory of their illness. Even then, the most likely way forward is that these services become nurse-led in each unit, with a few 'centres of excellence' incorporating the whole team, as described above, having a role as both educators and resource units.

At the very least, it is exciting that such emphasis on holistic management of ESKD has accelerated in the past few years and looks likely to continue to grow.

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The logo for Purite, featuring a stylized green circle on the left and the word "Purite" in a green, sans-serif font to its right.

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