

# Designing and Implementing a Specialist Renal Palliative Care Service

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## Introduction

People with Advanced (Stage 5) Kidney Disease (AKD) may experience a number of symptoms in varying degrees of severity and it has been reported they carry as much symptom burden as patients with advanced cancer with similar associated levels of psychological distress and a significantly worsening functional status; demonstrating need for specialist palliative care intervention.

End Stage Renal Failure as a primary diagnosis accounted for three referrals (<1%) to the local hospice service in 2014/15, but accounts for 5% of all national deaths (National End of Life Intelligence Network, June 2010).

Incidence of End Stage Renal Failure is increasing due ageing population and co-morbidities – notably diabetes and hypertension.

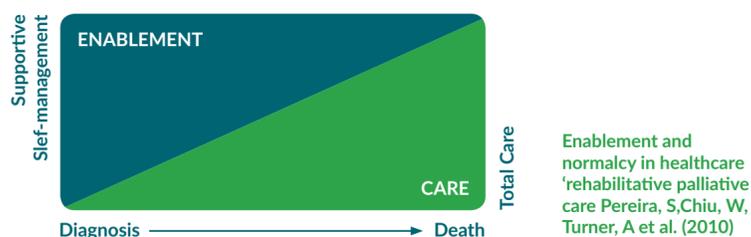
## National initiatives

Support people with advanced renal disease to live life as fully as possible and allow them to die with dignity in a setting of their choice (End of Life Care in Advanced Kidney Disease: A Framework for Implementation 2015).

Currently 81% of End Stage Renal Failure patients die in hospital.

NHS England (Ambitions for palliative and end of life care. A national framework for local action 2015-2020) recognises inequality of palliative and end of life care for long term conditions.

Rehabilitative palliative care concept - live well until death.



## Local pioneering approach

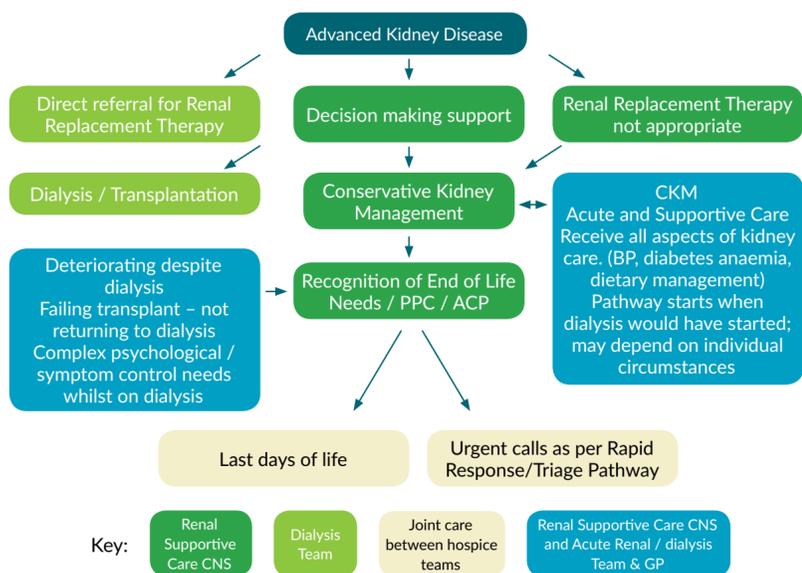
St Barnabas House: "We believe everyone deserves the chance to have St Barnabas' care at the end of their life".

Hospice Care Pioneers - roles created for long-term conditions (End Stage Renal Failure, Heart Failure, Liver Failure and Dementia).

Collaborative working – individually tailored informed choices, treatment of condition vital for symptom control quality and longevity of life.

Importance of collaboration with acute service providers to ensure informed and appropriate individualised decision - minimise renal decline, decrease symptom burden and maximise independence.

Access to rehabilitative palliative care – physiotherapy, support, Voluntary Services, Family Services Team.



## Criteria for referral:

- Asymptomatic persistently low eGFR  $\leq 10$  (unexplained and not related to an acute event) for Advance Care Planning.
- Significant symptom control, psychological or family/social issues and eGFR  $\leq 15$ .
- Diagnosis of Advanced Kidney Disease: Experiencing difficulties in deciding whether to have dialysis or choose conservative management, particularly when there are issues of family conflict, impaired capacity, or complex concurrent disease.
- Advanced Kidney Disease (usually eGFR  $\leq 15$ ): Decision made for Conservative Management.
- Approaching the last few weeks of life and not previously referred.
- Progressing poorly on dialysis and experiencing significant and troublesome symptoms.
- Considering discontinuing dialysis.
- Entered onto Trigger for Concern Register by Renal Team at Worthing Hospital or Sussex Kidney Unit and discussed at Local Complex Care non-Malignant Renal MDM.

Individuals who do not meet above criteria but have a diagnosis of Advanced Kidney Disease and would benefit from accessing support services and the opportunity for Advance Care Planning will also be accepted following discussion with the Clinical Nurse Specialist.

## Referrals accepted from:

- Worthing Hospital Renal Team: medical and Specialist Nurses
- Dialysis Unit Team (Sussex Kidney Unit)
- Primary Care: GP/Community Nurses
- Allied health professionals from primary and secondary care

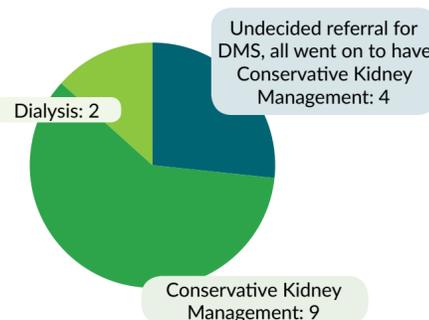
## Job plan

Day	Morning	Lunchtime	Afternoon
Monday	CNS phone clinic Community / dialysis unit Visits		CNS hospice clinic: Symptom Control, Advance Care Planning, Support. Opportunity for joint clinic with palliative care consultant if required
Tuesday			
Wednesday			
Thursday	Phone clinic Community / dialysis Visits Monthly joint clinic with Lead Renal Nurse Practitioner – Decision Making / Renal Replacement Therapy / Conservative Management	MDM monthly	Parallel clinic with Renal Team (consultant, CKD and anaemia nurses) – referred to discuss CKM as treatment choice. Introduce service Monthly joint clinic with CKD/hypertension CNS
Friday	phone clinic Triage referrals		Service Evaluation / Development Monthly caseload review

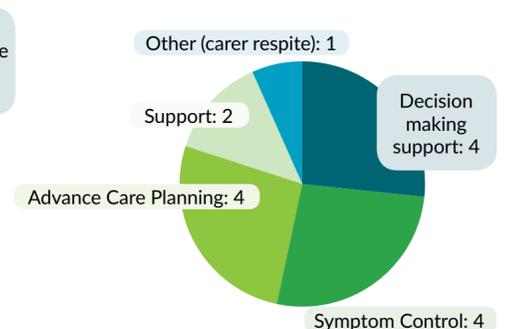
## KPIs

- First 3 months 18 referrals (3 in previous 12 months <1%).
- Total St Barnabas House referrals in the same time frame = 319 so equates to 5.6% of total referrals (a fivefold increase).
- 4.7% (15) of these on Renal Clinical Nurse Specialist caseload.
- Reasons for not on renal caseload: rapid deterioration, urgent referral while Clinical Nurse Specialist away (both by Community Team not under Renal Team), one out of area – stopping dialysis.

Treatment at time of referral:



Primary reason for referral:



- Total number having Advanced Care Planning – 11 (73.3%).
- Accessed one or more of support services (Day Hospice, Family Services, respite, physiotherapy, carers support group) 10 (66%).

## Future:

- Supportive care programme (to include legal and financial advice, practical advice and emotional support).
- Increase Primary care referrals.
- Increase stopping dialysis referrals in reasonable time to provide opportunity for Advanced Care Planning.
- Hospice out-patient provision of: iron infusion, EPO injection education and improve access to blood transfusions.

## Planned feedback mechanisms

Feedback post Clinical Nurse Specialist clinic: Symptom improvement following Clinical Nurse Specialist interaction. Opportunity for Advanced Care Planning, Preferred Place of Death, satisfaction – patient and carer

- Voices survey.
- Realtime feedback questionnaire post CNS clinic.
- Symptom Improvement post CNS interaction.
- Opportunity for Advance Care Planning.
- Preferred Place of Death achieved.
- Patient/carer satisfaction surveys.

## Bibliography

- How can we improve targeting a frail elderly patients to a deriatric day hospital rehab programme. Pereira, S, Chiu, W, Turner, A et al. 82. s.l.: BMC Geriatrics, 2010. Vol. 10.
- ESKD: A survey of recent research to support a palliative approach. Crawford, G, Robinson, J, Baker, A and Crail, S. 3. s.l.: American Journal of Hospital and Palliative Medicine, 2014. Vol. 31. 331 - 337.
- Needs Assessment for patients with non-malignant disease. Ford - Dunn, S. Worthing, West Sussex: s.n., 2014.
- The level of need for palliative care: a systematic review of the literature. Franks, P, Salisbury, C, Bosanquet, N, Wilkinson, E et al. s.l.: Palliative medicine, 2000. Vol. 14. 93 - 104.
- Palliative Care for Advanced Renal Disease: a summary of the evidence and future direction. Kane, P, Vinen, K and Murtagh F. 9. s.l.: Palliative Medicine, 2013. Vol. 27. 817 - 821.
- Understanding symptoms in patients with advanced chronic kidney disease managed without dialysis: use of a short patient-completed assessment tool. Murphy, E, Murtagh, F, Carey, I and Sheerin, N. s.l.: Nephron Clinical Practice, 2009. Vol. 111. c74 - c80.
- Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. Saini, T, Murtagh, F, Dupont P et al. s.l.: Palliative Medicine, 2006. Vol. 20. 631 - 636.
- Palliative care in Advanced Kidney Disease: a nurse-led joint renal and specialist palliative care clinic. Harrison, K and Watson, S. 1. s.l.: International Journal of Palliative Nursing, 2011. Vol. 17. 42 - 46.
- NHS. What's Important to me. A review of choice in End of Life Care. s.l.: The Choice in End of Life Programme Board, 2015.
- NHS Kidney Care End of Life. End of Life in Advanced Kidney Disease: a framework for implementation. England: NHS, 2015.
- Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 National Palliative and End of Life Care Partnership www.endoflifecareambitions.org.uk
- National End of Life Intelligence Network. Deaths from renal disease in England 2001 - 2008. National End of Life programme June 2010

