Introduction to the Concept of Renal Supportive Care

RSC Education Day

Elizabeth Josland CNC

2016

Objectives

- To understand the interface between Nephrology and Palliative Care and the role of Renal Supportive Care.
- To learn the structure and function of a Renal Supportive Care Service.
- Gain basic understanding of our clinic and adapt this for your own area

What is Renal Supportive Care?

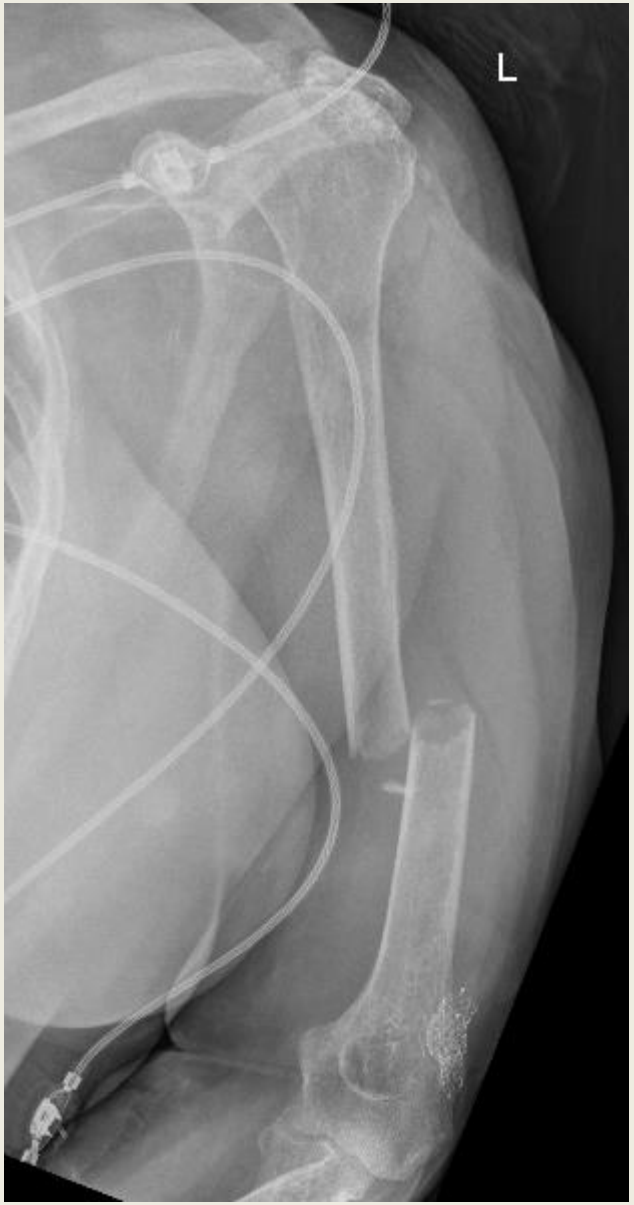
- How does it differ from palliative care?

- What team members are required to make a service successful?

Supportive Care definition

- “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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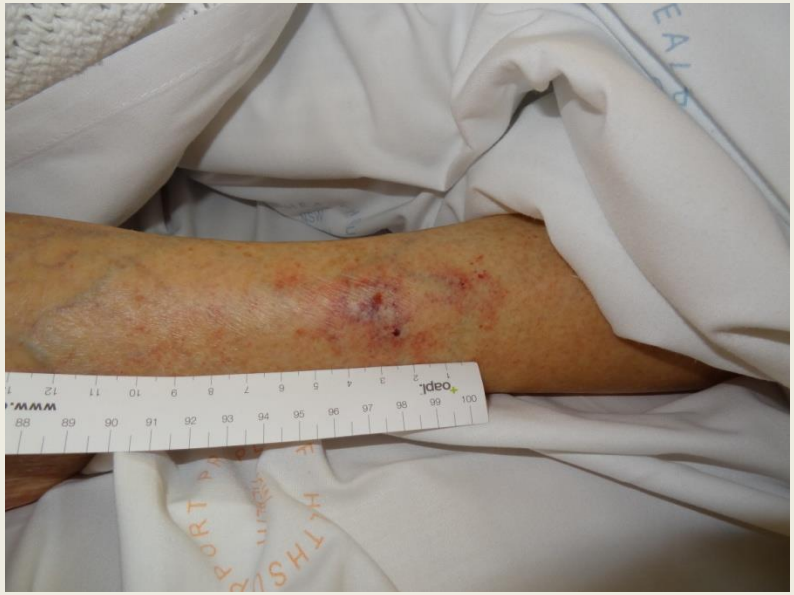
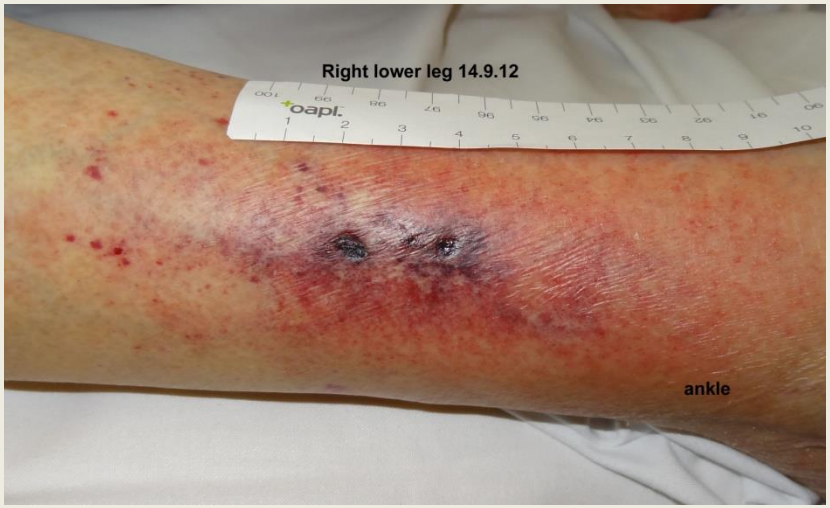



Right lower leg 14.9.12
ankle

Palliative Care Definition

- “The active total care of patients whose disease is not responsive to curative treatment…..the goal of palliative care is to achieve the best quality of life for patients and their families”

WHO definition of palliative care

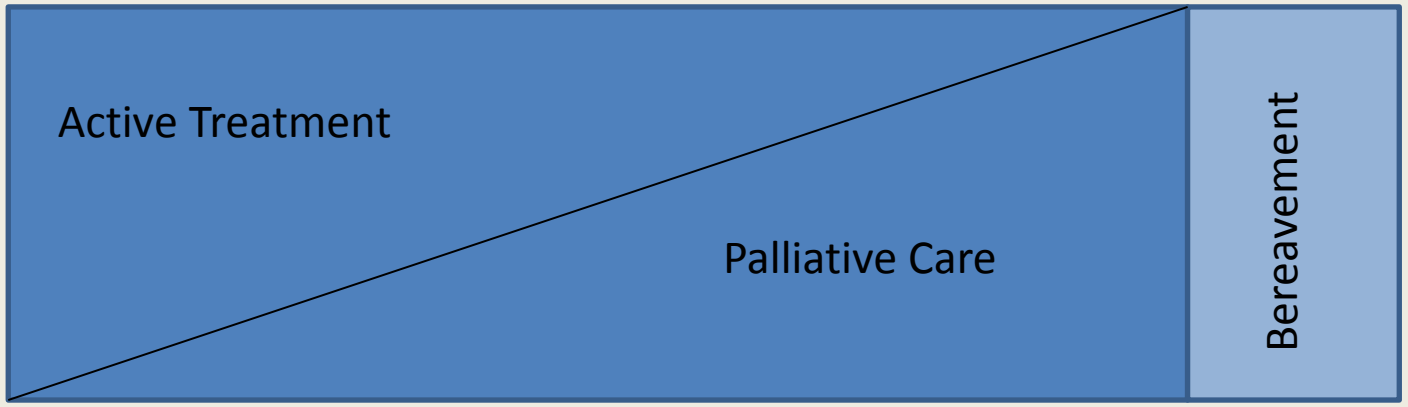
What does conservative management mean for the patient?

- Continue with all CKD measures to:
  - Slow the deterioration of renal function
  - Minimise complications of renal disease
  - Manage symptoms
- Also:
  - Support for carers and patients (diet, social work, psychological)
  - End of life planning (choices, substitute decision maker)

History of RSC at St George

- Idea began back in 2005
- Based on poor QoL, ANZDATA high number of ‘social’ causes of death
- High symptom burden of dialysis patients identified in a study at this hospital
- Identified an unmet need for symptom management in the dialysis group
- The patients were very happy with palliative care appointments
- Word of mouth through patient telegraph found more patients wanting the service and asking

Paradigm


Active Treatment
Palliative Care
Bereavement


Stable eGFR
Falling eGFR
Deterioration
Intensive period
Family follow up

Referral Pathways

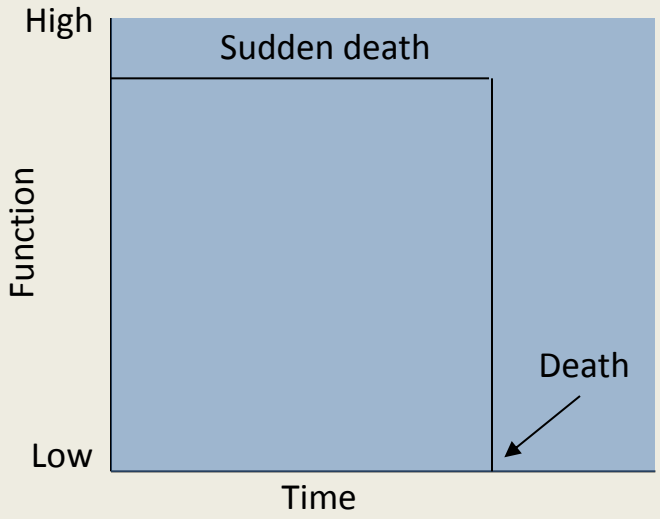
- Pre dialysis clinic ⇨ NFD decision ⇨ RSC clinic as well as nephrologist (GP referral)
- Nephrologist decides NFD ⇨ Also seen by RSC
- Inpatient from other health service seen by RSC ⇨ Discharged back to own health service
- Dialysis nurse refers to RSC nurse or patient self refers ⇨ Talk to nephrologist and see if appropriate

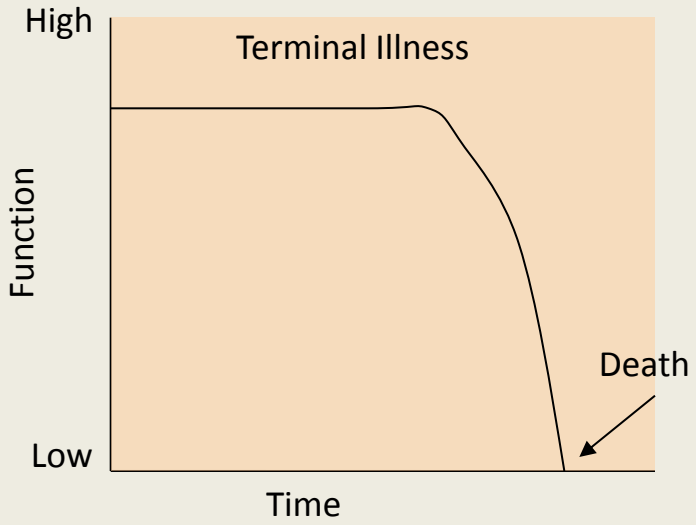
Referral Pathways

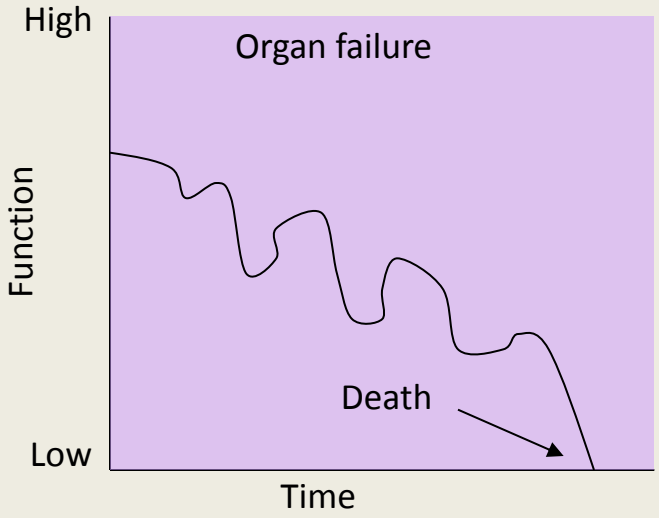
- Renal team refer inpatient to RSC ⇨ Nurse sees patient and seeks advice from palliative care if required. Ward rounds on occasion. ⇨ Discharge planning re follow up
- Patient for EOL care at home ⇨ Community Palliative Care Team
- New NFD patient to clinic ⇨ allied health team

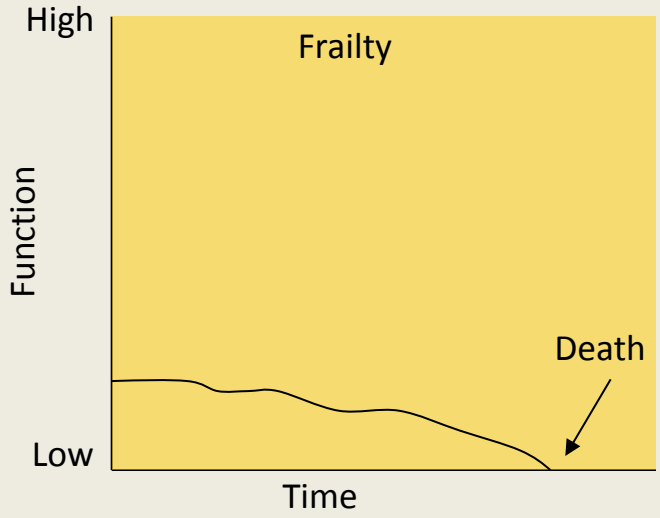
Knowledge patients expect from you as a RSC expert

- Basic renal failure progression
- Basic dialysis knowledge
  - What it is and how it works
- Symptom management knowledge for monitoring and managing
- Community services available to them
- Referral guidelines to hospice (don’t give incorrect information such as it is available when it isn’t)
- What they can eat to keep them as well and symptom free as possible
- That they are supported in whatever decision they make but can talk to you if they have questions.









Chambers, J. Brown, E. Germain, M. 2010. Supportive Care for the Renal Patient. Second Edition. Page 284

Inpatients

- Referrals come straight from the teams
  - Renal
  - Aged care
  - Palliative
- What the team asking for?
  - ?ESKD nearing EOL
  - ?Introduction to team with view to requiring ongoing clinic support
  - Appropriateness (do you need to refer onwards)
  - Discharge planning – how much follow up is required from you
  - Assess medication chart (renal appropriate), what they are already taking, what has been tried in the past
  - Re-examine what has not worked and why

Outpatients

- Referral from nephrology usually
- Follow up dependant on stage of renal failure, symptom burden, treatments implemented
- Dialysis patients (follow up in clinic or on dialysis)
- RSC nurse to follow up in dialysis
- Dialysis nurses can refer to RSC nurse

Clinic

- Palliative care physician
  - Important for complex palliative symptom management and fast prescribing. Does require help with dialysis related questions.
- Nurse practitioner would be ideal in the role
- Nurse requirements:
  - Provide basic dialysis information to patient or palliative care consultant if required
  - Initiate community referrals
  - Contact social work and/or dietitian
  - Organise future follow up (clinic, outpatient, phone etc)
  - Surveys and demographic collection
  - Time management of clinics

Clinic

- Social work
  - Blanket referral for conservative patients
  - Any social / emotional issues
- Dietitian
  - Blanket referral for conservative patients
  - Important for symptom prevention
  - Any diet issues
  - Required more and more as appetite decreases and may need renal specific supplements which can be prescribed for a reduced cost to family

Withdrawal of treatment

- Important to differentiate difference between withdrawing a futile treatment and suicide or euthanasia if family talk about it.

- Reading material available “An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death”

Groups

- Discuss a case in each group
- Consider
  - Where does the RSC referral come from?
  - What if the patient has never been seen by a nephrologist or the nephrologist is not in your local health service?
  - What can RSC do for this patient?
  - How would you monitor the patient?
  - As the patient deteriorates, what other services are you going to have to introduce and how would you do this?
  - What type of conversations would occur and how do you communicate to other health providers involved in each case?
  - How would you raise the profile of RSC in the hospital?

Remembrance

Renal Memorial Service

23rd May 2013

Recommended Resources/Reading

- Chambers, E. J., Brown, E., & Germain, M. (2010). *Supportive Care for the Renal Patient* (2nd ed.). New York: Oxford University Press.
- Davison, S. N., Koncicki, H., & Brennan, F. (2014). Pain in chronic kidney disease: a scoping review. *Semin Dial, 27*(2), 188-204.
- Koncicki, H., Brennan, F., Vinen, K., & SN, D. (2015). An Approach to Pain Management in End Stage REnal Disease: Considerations for General Management and Intradialytic Symptoms. *Seminars in Dialysis*, 1-8.
- Brown, M. A., Crail, S. M., Masterson, R., Foote, C., Robins, J., Katz, I., et al. (2013). ANZSN renal supportive care guidelines 2013. *Nephrology, 18*(6), 401-454.
- http://www0.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_056.pdf