Nursing Role in Renal Supportive Care. How far have we come and where to from here?

Renal Supportive Care Symposium 2015

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St George Hospital
Content

• Definition of Supportive Care
• Renal Supportive Care at St George and becoming a state-wide service
• Aim of the service
• Model of care
• Multi-disciplinary team
• Inpatient and outpatient management
• End of life care
• Measuring outcomes of service
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
History of Renal Supportive Care at St George Hospital

• Pilot study in 2005 to measure symptoms of patients who attend hospital haemodialysis.
• Results showed a high symptom burden and also showed a great acceptance of the palliative service for symptom management.
• The regular service commenced fortnightly from March 2009, weekly from November 2010, twice weekly August 2011.
• Funding commenced in May 2012 (CNC1 0.5 FTE) and has grown to 1.6 CNCs as of August 2015 as part of a state-wide initiative.
• Services Provided
  - Inpatients
  - Outpatients
    - Clinics
    - Phone consultations and case planning
    - Home and nursing home visits (from Dec 2012)
Growth to a State-wide Renal Supportive Care Service

March 2009 to 2015
Consultative Process

• ACI Renal Supportive Care Working Group

• This is a new model of care is underpinned by three key principles:

• Patients do not travel to receive this expert care; instead, staff travel or connect via media with a centre expert in this process in order to learn the expertise of renal supportive care and bring these skills to their patients.

• This is a nurse led model, underpinned by ongoing education, with active involvement of patients and their families at every stage.

• Early use of the expertise and principles of Palliative Care are crucial to the success of the model of care
• Developed by a multi-disciplinary group of doctors, nurses and allied health staff from a range of hospitals around NSW with the support of the ACI Renal and Palliative Care Networks’ managers.

• There has been extensive consultation with NSW renal units:
  – Survey to understand the gaps in service
  – Formal presentation at the NSW Renal Group
  – Written feedback from heads of renal units and other renal staff with responses from 76% of all renal departments across NSW.
Aim of the service

- To provide a formal structured conservative pathway where appropriate
- Provide complex symptom management to patients with kidney disease
- To assist patients, families and clinicians in treatment decision making (initiation or withdrawal) where required
- Provide holistic care at a place close to their home for patients with ESKD.
- Provide patients with ESKD to opportunity to discuss and initiate an Advance Care Plan in a timely fashion
Proposed Model of Care

Nurse-driven hospital - and community-based chronic care model underpinned by 6 key elements
# Proposed Model of Care based on the Cancer Services Model of Care

<table>
<thead>
<tr>
<th></th>
<th>Patient and family involvement</th>
<th>Multidisciplinary care with primary care involvement and agreed education &amp; referral pathways</th>
<th>Clinical leadership</th>
<th>Education and continuing professional development</th>
<th>Quality assurance</th>
<th>Research</th>
</tr>
</thead>
</table>
| 1 | • Engaged in planning and evaluation of services  
   • Access to information based on best available evidence | • People to have as much of their treatment as close to home as possible  
   • Clinicians use agreed referral pathways, primarily for staff education  
   • Primary care involved in diagnosis, referral and shared care | • Identify, support and develop ‘clinical champions’ in each Renal unit  
   • Liaise with ACI, government and departmental decision makers  
   • Lead operational and clinical governance  
   • Implement practice based on best available evidence | • Mentoring and clinical supervision  
   • Web based clinical protocols for nurses, dietitians, specialists and primary care  
   • RSC education for non-palliative care nurses, specialists and primary care | • Clinical audit by each Unit  
   • Guidelines developed by each ‘Hub’  
   • Data collected to improve outcomes | • Development of a program of research including clinical trials that improve clinician and patient decision making and patient and caregiver outcomes |
Hubs

• Central source of easily available resources
  – Educational materials
  – Clinical Guidelines
  – Clinical Education

• Provide training and education to staff from their allocated hospitals. These staff return to their workplace and become the ‘champion’ within their own unit to continue to educate others.

• A designated Nephrologist will oversee the RSC program within their Hub.
## Hubs and affiliated LHD

<table>
<thead>
<tr>
<th>St George Hospital</th>
<th>John Hunter Hospital</th>
<th>Nepean Hospital</th>
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<tbody>
<tr>
<td>St Vincent’s Hospital</td>
<td>Central Coast LHD</td>
<td>Western Sydney LHD</td>
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<tr>
<td>Northern Sydney LHD</td>
<td>Northern NSW LHD</td>
<td>South Western Sydney LHD</td>
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<td>South Eastern Sydney LHD</td>
<td>Mid North Coast LHD</td>
<td>Nepean Blue Mountains LHD</td>
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<td>Sydney LHD</td>
<td>Hunter New England LHD</td>
<td>Murrumbidgee LHD</td>
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<td>Illawarra Shoalhaven LHD</td>
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<td>Western NSW LHD</td>
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<td>Far West LHD</td>
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Hub requirements

• Large renal unit (servicing approx. 200 patients)
• Nephrologist to become the Director of RSC service
• Palliative care consultant
• CNC 1.5 FTE
• Appropriate level of Allied health staffing
• Administrative support plus Research officer
• Infrastructure support (office, desk space, IT etc)
• Education program to provide a networked model of specialist renal palliative care (learn from us and take the skills back to your area i.e staff travel but patients do not)
KPIs

- Demographics
- Proportion conservative stage 4 or 5 CKD seen by RSC
- Proportion of dialysis withdrawal patients seen by RSC
- Proportion seen by RSC for symptom management
- Number of occasions of service for clinic
- Change in iPOS score after 3 and 6 months
- Change in functional status after 3 and 6 months (Australian Karnofsky)
- Change in nutritional status after 3 and 6 months (SGA)
- Patient/family satisfaction
- Patients wishes for end of life care documented and available
- % of RSC patients and RSC conservative patients who had nutritional assessment
- % of RSC patients and RSC conservative patients who had a social work assessment
Symptom tool – iPOS-S Renal


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**IPOS-Renal Patient Version**

<table>
<thead>
<tr>
<th>Patient name</th>
<th>Date (dd/mm/yyyy)</th>
<th>Patient number</th>
<th>(for staff use)</th>
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</table>

**Q1. What have been your main problems or concerns over the past week??**

1. 
2. 
3. 

**Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?**

<table>
<thead>
<tr>
<th>Pain</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Severely</th>
<th>Overwhelmingly</th>
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<tr>
<td>Shortness of breath</td>
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<td>Weakness or lack of energy</td>
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<tr>
<td>Nausea (feeling like you are going to be sick)</td>
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<tr>
<td>Vomiting (being sick)</td>
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<td></td>
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<tr>
<td>Poor appetite</td>
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<tr>
<td>Constipation</td>
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<tr>
<td>Sore or dry mouth</td>
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<td>Drowsiness</td>
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<td>Poor mobility</td>
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<tr>
<td>Itching</td>
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<td>Difficulty Sleeping</td>
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<td>Restless legs or difficulty keeping legs still</td>
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<tr>
<td>Changes in skin</td>
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<tr>
<td>Diarrhoea</td>
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</table>

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week:

1. 
2. 
3. 

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**Over the past week:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Q3. Have you been feeling anxious or worried about your illness or treatment?</td>
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<td>Q4. Have any of your family or friends been anxious or worried about you?</td>
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<td>Q5. Have you been feeling depressed?</td>
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<td>Q6. Have you felt at peace?</td>
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<tr>
<td>Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?</td>
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<td>Q8. Have you had as much information as you wanted?</td>
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<tr>
<td>Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)</td>
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<td>Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests</td>
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<tr>
<td>Q11. How did you complete this questionnaire?</td>
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</table>

*If you are worried about any of the issues raised on this questionnaire, then please speak to your doctor or nurse.*
Accountability

• Progress reports to the ACI from Hubs include recruitment, provision of education and guideline / protocol development

• Reports of patient activity and KPIs from all LHDs to evaluate the service 2016/17

• Outcomes will be reported via the ACI to NSW Ministry of Health
Multidisciplinary Team

- Nephrologist
- Palliative Care Consultant
- CNC (or nurse practitioner)
- Social Worker
- Dietitian
- Other disciplines involved
- GP
- Pharmacist
• Patient and family central to care
• Coordination and communication of care
• Education
• Quality Improvement
• Respecting choices
• Prevent avoidable admissions
Communication

• Essential to open the communication between RSC and the network of carers involved with the patient
  - GP
  - Pharmacy
  - Nursing Home
  - Family / carer
  - Case workers

• RSC is a adjunct to the usual care, any changes **must** be communicated

• Area where this falls down repeatedly for any patient who sees multiple doctors
  - Medications
Management of Referrals

• How referrals arrive

– Nephrologists directly refer (inpatient and outpatient)
– Clinic referrals require a referral letter.
– Inpatient referrals come from any admitting team – patient must have renal failure and must speak directly to the RSC team (usually the CNC)
– Dialysis patients can be referred by the nurses, but always talk to the nephrologist first
Management of Referrals

• Who is appropriate for referral to RSC?
  
  – Dialysis patients with symptoms
  – Dialysis patients considering withdrawal or withdrawal imminent due to sentinel event
  – Dialysis patients with a 2nd life limiting illness
  – Conservatively managed patients (clinic is currently 2/3 conservative)
Establishing Referral Pathways for Community Services

- Every LDH will have their own systems in place
- Possible you may have to deal with multiple forms, guidelines, patient criteria etc.
- While developing your own RSC service be guided by services such as community palliative care in your area
- Learn the community service council boundaries
- Use the social worker to guide you
Consultative Team

- Do not take over care
- Adjuvant to their usual care
- Always in consultation with the nephrologist and other treating teams
Inpatient Management

- Talk to patient and family about symptoms, comfort, aim of care, discharge planning
- Review medication chart
  - Renal appropriate pain management
  - Are medications correct?
  - Is anything missing that should be there?
- Can the patient go home?
- Do we need to talk about nursing home or hospice?
- Family meetings
- If medication is being changed, educate the patient/family/staff as appropriate
- Changing from short acting to long acting opioids
- Care of the dying
- Care of the family and loved ones
Outpatient Management including Dialysis Patients

- Clinics
  - See patients before they have their consultation
  - Provide information regarding dialysis when questions arise
  - Follow up allied health if required

- See patients on dialysis

- Monitor changes in medications (does it help, or are there side effects?)

- Advance care plans onto an electronic medical record and also sent to GP
Withdrawal of Dialysis

• Usually as the result of a sentinel event
• Nephrologist always involved
• If there is time, hospice may be appropriate or transfer home with community palliative care support
• If a patient wants to stop dialysis for psychosocial reasons, this usually happens after a long comprehensive consultations
End of Life Care

• End of life medications adjusted for renal failure
• PRN medications to relieve avoidable suffering
• Offers closure to the family following a long illness
• The priority is the comfort of the patient
• Unrealistic expectations avoided
• Communication skills are paramount (remember the patient may still be able to hear)
• Re-Consider bedside consultations in 4 bed rooms
• Diagnosis of dying is important (family have often never seen this before and rely on nurses to tell them that the patient’s condition has changed and time may be short)
End of Life Care

• Anticipatory prescribing

  – Pain
    – Hydromorphone 0.25-0.5mg Q2-4H sci prn for SOB or pain
      (may need regular dose if already using opioids)

  – Agitation
    – Haloperidol 0.5-1mg bd sci (nausea/delirium) can increase
    – Midazolam 2.5-5mg Q2-4H sci prn for ongoing agitation
- Terminal secretions (renal failure)
  - Glycopyrrolate 200-400mcg Q2-4H sci prn (can use Atropine 1% eyedrops 2 drops tds SL plus prn dose 2-4 drops Q4-6hr; or Buscopan 20mg sci Q4H plus prn Q2-4hrs)

- Anxiety related to SOB
  - Lorazepam 0.5-1mg SL bd – tds prn for anxiety

- Myoclonic jerks (or epileptic)
  - Clonazepam 0.25-0.5mg bd SL prn
Guidelines

• Available on our website:

http://stgrenal.org.au/
Pain

Patient is in pain

Patient's pain is controlled

Patient is already taking oral opioids

Yes

If the patient is already taking strong opioids, contact the Palliative Care Team

No

Hydromorphone 0.25 – 0.5 mg Q4H s/c and 0.25-0.5 mg sci prn q 2-4 hours.

Supportive Information:

To convert from other strong opioids contact the Palliative Care Team / Pharmacy for further advice & support as needed.

Morphine and its metabolites are most likely to cause toxicity (myoclonic jerks, profound narcosis and respiratory depression) and is not recommended. In a patient who is unable to swallow, Hydromorphone or Fentanyl in regular subcutaneous doses or in a continuous infusion is recommended. Transdermal Fentanyl may also be prescribed.

If symptoms persist contact the Palliative Care Team

Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
Respiratory Tract / Terminal Secretions

- Present
  - Treatments include:
    1. Glycopyrrolate 200 mcg (0.2 mg) s/c prn q 1-2 hours.
    2. Atropine 1% eye drops sublingually 2 drops tds and prn 2-4 drops q 4-6 hours.
    3. Hyoscine butylbromide (Buscopan) 20mg sc q4 hours and prn q 2-4 hours.
  - If three or more doses of prn Glycopyrrolate or Buscopan are required then consider commencing a continuous infusion via syringe driver.
    - For Glycopyrrolate approx doses of 2.4-3.2 mg over 24 hours;
      for Buscopan 80-240mg over 24 hours.

- Absent
  - Chart on prn order as per ‘Present’ to cover the potential presentation of the symptom.

Supportive Information
If symptoms persist contact the Palliative Care Team

Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay responding to a symptom if it occurs.

NOTE: Hyoscine Hydrobromide is not recommended due to permeability of the blood/brain barrier in uraemia and a consequent risk of paradoxical agitation.
Conclusion

• Renal Supportive Care Service is:
  – Consultative service
  – Nurse led
  – Embedded within the existing renal service
  – Led by a local nephrologist
  – Networked model (Hub to meet training and mentoring and resource needs)

• Requires staff to collect data to report outcomes

• Resources to be shared with the whole state-wide service

• LHDs to develop their service to suit their own service (metro vs rural)
• Thank you