

# 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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# 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

1. Patient and family involvement	<ul style="list-style-type: none"> <li>• Engaged in planning and evaluation of services</li> <li>• Access to information based on best available evidence</li> </ul>
2. Multidisciplinary care with primary care involvement and agreed education & referral pathways	<ul style="list-style-type: none"> <li>• People to have as much of their treatment as close to home as possible</li> <li>• Clinicians use agreed referral pathways, primarily for staff education</li> <li>• Primary care involved in diagnosis, referral and shared care</li> </ul>
3. Clinical leadership	<ul style="list-style-type: none"> <li>• Identify, support and develop 'clinical champions' in each Renal unit</li> <li>• Liaise with ACI, government and departmental decision makers</li> <li>• Lead operational and clinical governance</li> <li>• Implement practice based on best available evidence</li> </ul>
4. Education and continuing professional development	<ul style="list-style-type: none"> <li>• Mentoring and clinical supervision</li> <li>• Web based clinical protocols for nurses, dietitians, specialists and primary care</li> <li>• RSC education for non-palliative care nurses, specialists and primary care</li> </ul>
5. Quality assurance	<ul style="list-style-type: none"> <li>• Clinical audit by each Unit</li> <li>• Guidelines developed by each 'Hub'</li> <li>• Data collected to improve outcomes</li> </ul>
6. Research	<ul style="list-style-type: none"> <li>• Development of a program of research including clinical trials that improve clinician and patient decision making and patient and caregiver outcomes</li> </ul>

# 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

St George Hospital	John Hunter Hospital	Nepean Hospital
St Vincent's Hospital	Central Coast LHD	Western Sydney LHD
Northern Sydney LHD	Northern NSW LHD	South Western Sydney LHD
South Eastern Sydney LHD	Mid North Coast LHD	Nepean Blue Mountains LHD
Sydney LHD	Hunter New England LHD	Murrumbidgee LHD
Illawarra Shoalhaven LHD		Southern NSW LHD
Western NSW LHD		
Far West LHD		

# 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

## IPOS-Renal Patient Version



www.pos-pal.org

Patient name : .....  
 Date (dd/mm/yyyy) : .....  
 Patient number : ..... (for staff use)

### 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?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Itching	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Difficulty Sleeping	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Restless legs or difficulty keeping legs still	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Changes in skin	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Diarrhoea	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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

1. ....	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
2. ....	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
3. ....	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Available by registering on the Cicely Saunders POS website <http://pos-pal.org/maix/>

**Over the past week:**

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	None at all		Up to half a day wasted	More than half a day wasted	
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	0 <input type="checkbox"/>		1 <input type="checkbox"/>	2 <input type="checkbox"/>	
	On my own		With help from a friend or relative		With help from a member of staff
Q11. How did you complete this questionnaire?	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>

**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 2<sup>nd</sup> 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

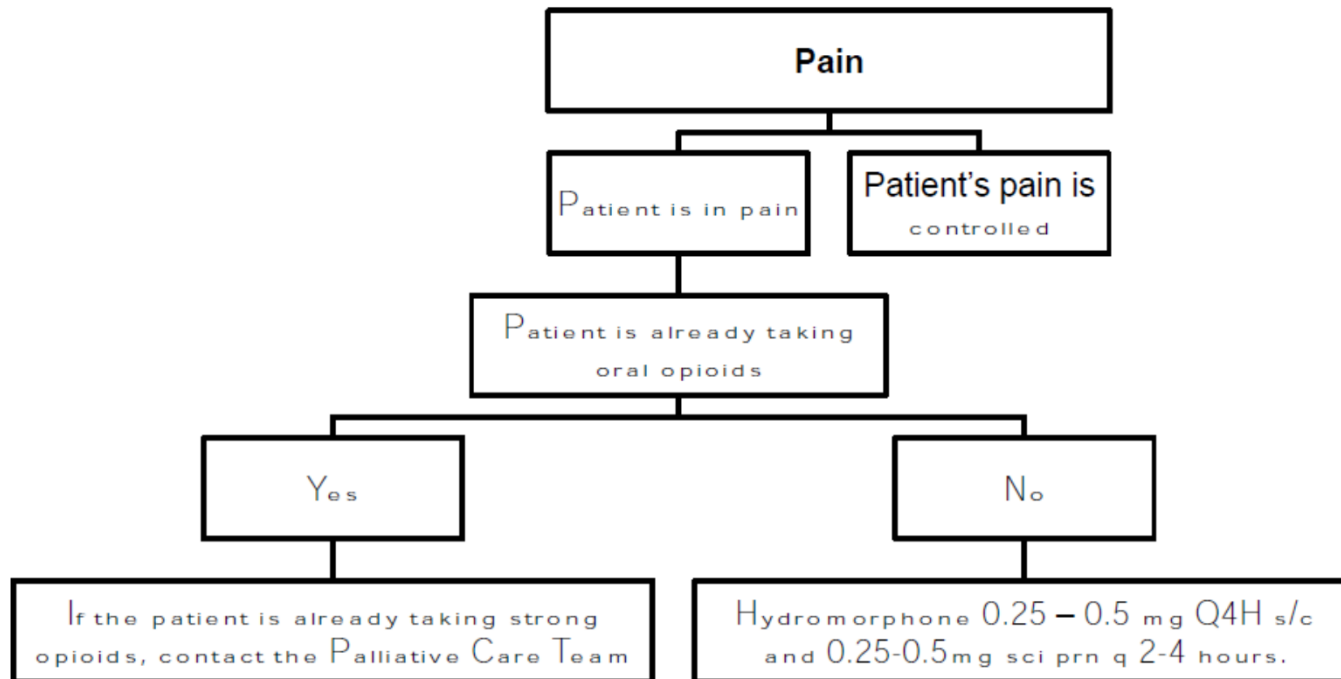
- Anticipatory prescribing
  - Pain
    - Hydromorphone 0.25-0.5mg Q2-4H sci prn for SOB or pain (may need regular dose if already using opioids)
  - Agitation
    - Haloperidol 0.5-1mg bd sci (nausea/delirium) can increase
    - Midazolam 2.5-5mg Q2-4H sci prn for ongoing agitation

- 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/>



Supportive Information:

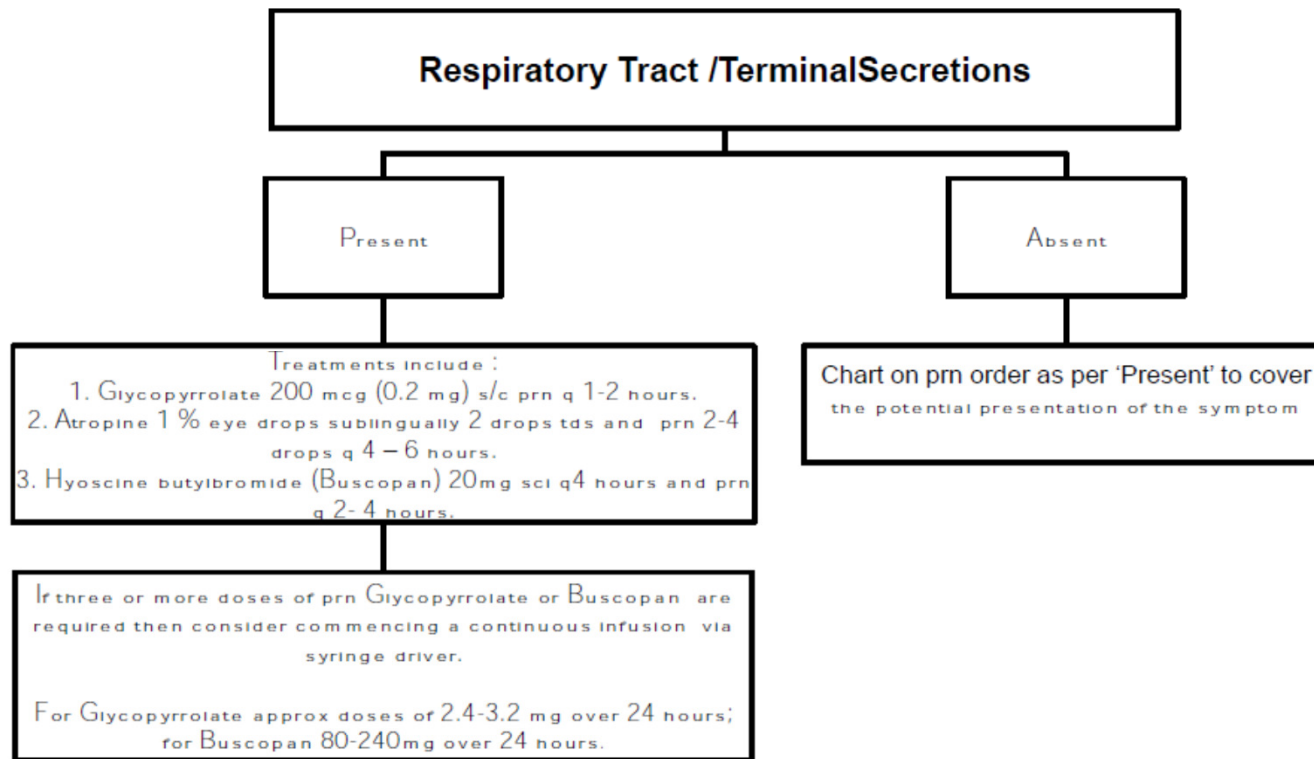
To convert from other strong opioids contact the Palliative Care Team / Pharmacy for further advice & support as needed.

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.





Supportive Information

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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)

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- Thank you