



Health
South Eastern Sydney
Local Health District



ESCALATING PATIENT & CARER NEEDS TOWARDS END OF LIFE; OVERVIEW OF END OF LIFE CARE IN THE COMMUNITY

Renal Supportive Care Nursing
Elizabeth Josland CNC



Objectives

- Dialysis vs non-dialysis end of life picture
- Survival
- Causes of death
- Issues encountered – community needs
- Case
- End of life

The Renal Supportive Care Client

Dialysis Symptom Support

- Average age: 72 years
- When does end of life occur?
 - Sentinel event
 - Deterioration over time (age related or comorbidity related)
 - QOL decision
 - Prognosis on ceasing dialysis: days to months dependant on urine output and health

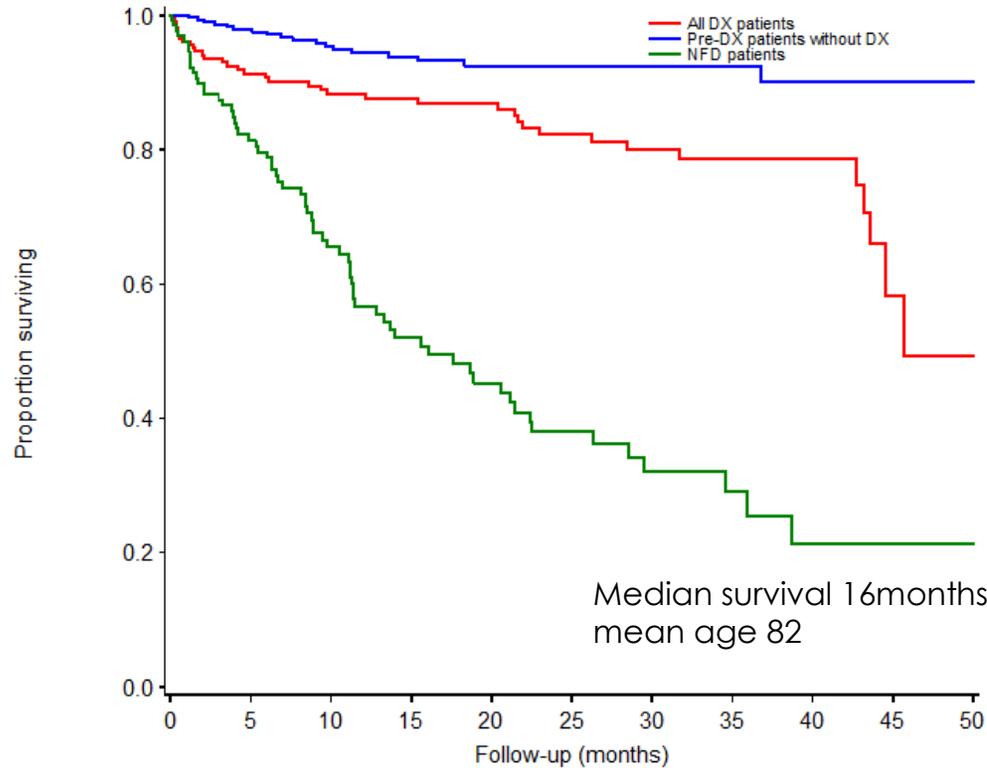
Non-Dialysis

- Average age: 84 years
- When does end of life occur?
 - Sentinel event
 - Gradual deterioration (age, renal, other comorbidity)
 - Prognosis if not for dialysis: Median survival was 16 months (CJASN 2015)
 - No statistical significant survival if >75yrs with 2 or more comorbidities (one being IHD) for dialysis/NFD (CJASN 2015)

Why palliative care so early?

- Supportive/palliative care is appropriate for all chronic life limiting illnesses such as heart failure, respiratory failure, liver failure
- Early introduction to the team to avoid (some) anxiety at end of life
- Prevent avoidable admissions (fluid overload, SOB, carer acopia, pain crisis)
- Crisis planning (pre-empting what crisis may happen and plan for it with the carer or patient)
- End of life planning (ACPs, knowing place they prefer, knowing who the carer is and their capability, start conversations with GP)
- It takes time to develop a trusting relationship with clients

Survival



CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life

Mark A. Brown,* Gemma K. Collett,* Elizabeth A. Josland,* Celine Foote,† Qiang Li,† and Frank P. Brennan*

SURVIVAL IN PATIENTS WHO REMAINED IN THE **PRE-DIALYSIS CLINIC** WITHOUT RECEIVING DIALYSIS (N=181) COMPARED WITH ALL THOSE **RECEIVING DIALYSIS** (N=164) AND PATIENTS IN THE **RSC-Not for dialysis GROUP** (N=122). (Arbitrarily defined as >70 years)

Time zero is from first attendance at the Pre-dialysis or Renal Supportive Care clinic after a decision had been made to pursue dialysis or not. For the “all dialysis” group this time point includes the time at first dialysis for the 72 patients who had not attended the Pre-dialysis clinic.

Causes of death

Table 2. Cause of death in patients in the RSC-NFD and predialysis groups

Cause of Death	RSC-NFD (<i>n</i> =68)	Predialysis (<i>n</i> =28)
Renal	42 (62)	5 (18)
Cardiac	9 (13)	13 (46)
Malignancy	8 (12)	4 (14)
Sepsis	2 (3)	2 (7)
Other	7 (10)	4 (14)

Data are presented as *n* (%). The distribution of causes of death differs between the two groups ($p=0.001$).

Undecided Treatment Pathway

Results	08/05/2017 08:35	04/05/2017 15:30	01/05/2017 09:59	30/04/2017 08:10
Blood Chemistries				
<input type="checkbox"/> Sodium Level	* 137 mmol/L		* 138 mmol/L	* 138 mmol/L
<input type="checkbox"/> Potassium Level	* 4.4 mmol/L		* 4.9 mmol/L	* 4.8 mmol/L
<input type="checkbox"/> Chloride Level	* L 88 mmol/L		* L 93 mmol/L	* L 93 mmol/L
<input type="checkbox"/> Bicarbonate Level	* L 21 mmol/L		* L 19 mmol/L	* 22 mmol/L
<input type="checkbox"/> Urea Level	* H 82.0 mmol/L		* H 68.3 mmol/L	* H 68.4 mmol/L
<input type="checkbox"/> Creatinine	* H 1,120 umol/L		* H 1,064 umol/L	* H 1,057 umol/L
<input type="checkbox"/> eGFR CKD-EPI	* 3 mL/min/1.73m		* 4 mL/min/1.73m	* 4 mL/min/1.73m
<input type="checkbox"/> Bilirubin Total				4 umol/L
<input type="checkbox"/> Protein Total Level				62 g/L
<input type="checkbox"/> Albumin Level	* L 23 g/L		* L 25 g/L	L 25 g/L, * L 25 g/L
<input type="checkbox"/> ALP				47 U/L
<input type="checkbox"/> GGT				47 U/L
<input type="checkbox"/> ALT				22 U/L
<input type="checkbox"/> Troponin T				18 U/L
<input type="checkbox"/> Creatinine Level	* L 95 mmol/L		* L 1.96 mmol/L	* L 1.97 mmol/L
<input type="checkbox"/> Corrected Calcium Level	* 2.15 mmol/L		* 2.15 mmol/L	* 2.16 mmol/L
<input type="checkbox"/> Iron Level				L 6.1 umol/L
<input type="checkbox"/> Iron Saturation				L 14.4 %
<input type="checkbox"/> Transferrin				L 1.7 g/L
<input type="checkbox"/> Ferritin				212 ug/L
<input type="checkbox"/> Magnesium Level	* H 1.15 mmol/L		* H 1.19 mmol/L	* H 1.13 mmol/L
<input type="checkbox"/> Phosphate Level	* C 4.64 mmol/L		* C 3.80 mmol/L	* C 3.59 mmol/L
<input type="checkbox"/> Urate Level				

The crisis

- Risk of a poor death
- Late conversations
- Missed opportunity to go home, get affairs in order, gather family...

Bleeding risk with vascular access

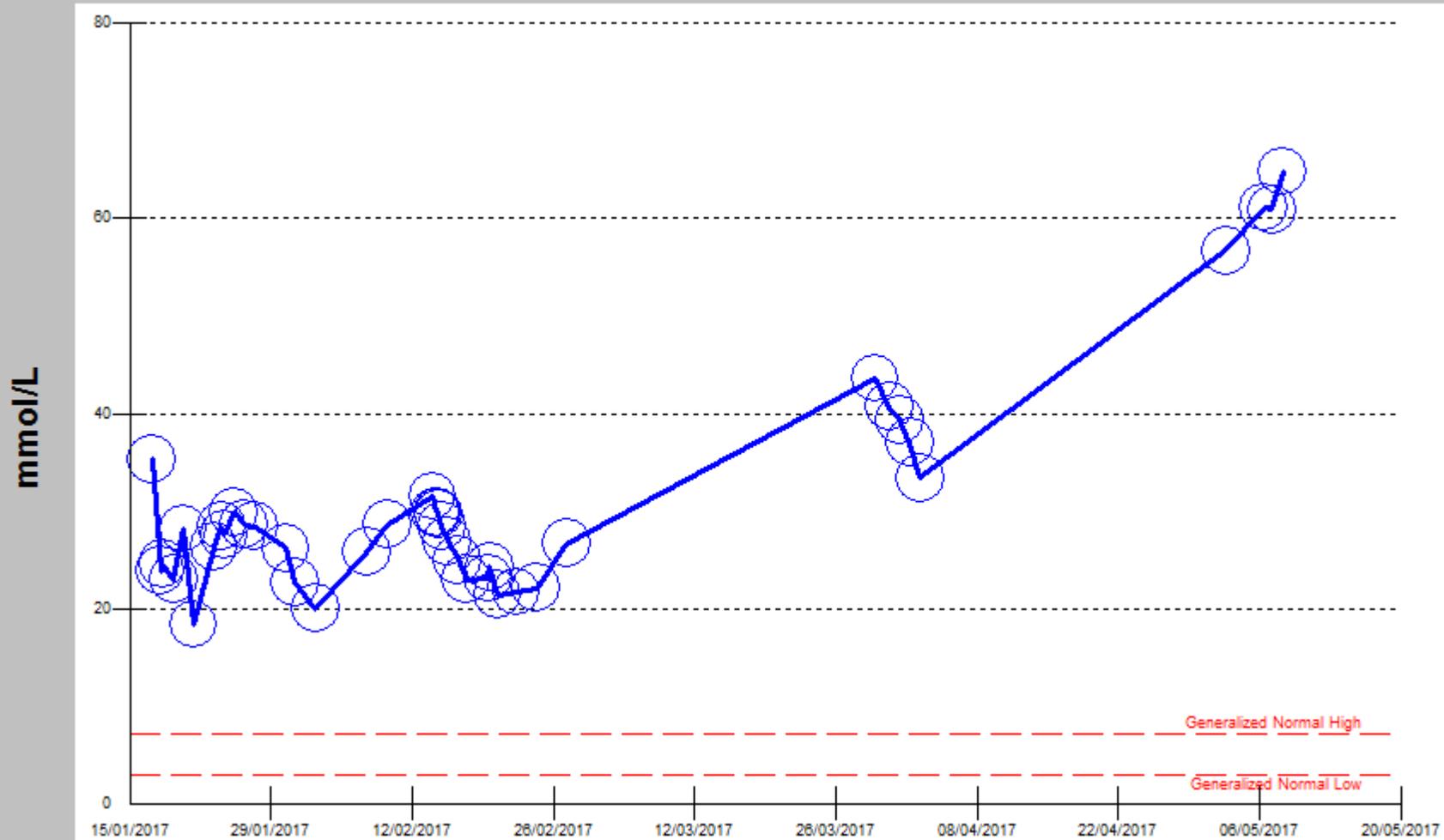
Vascath

Anxiety

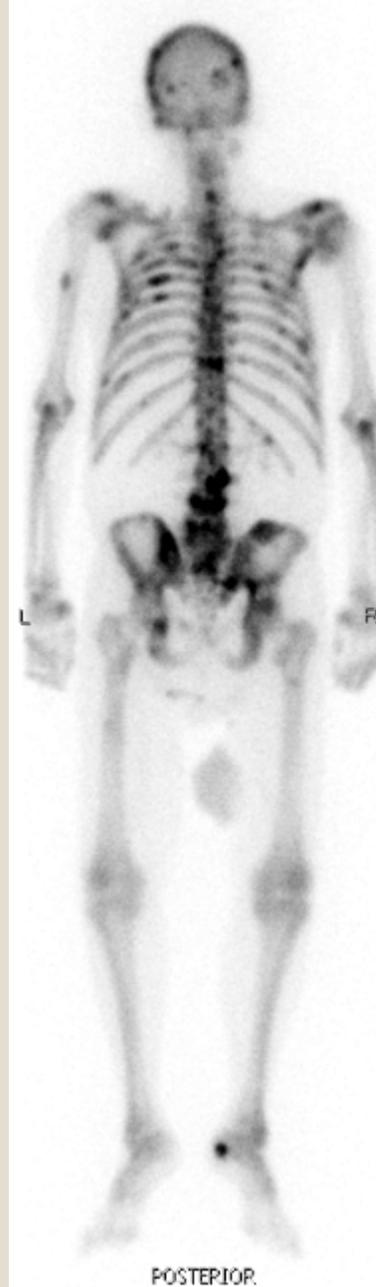
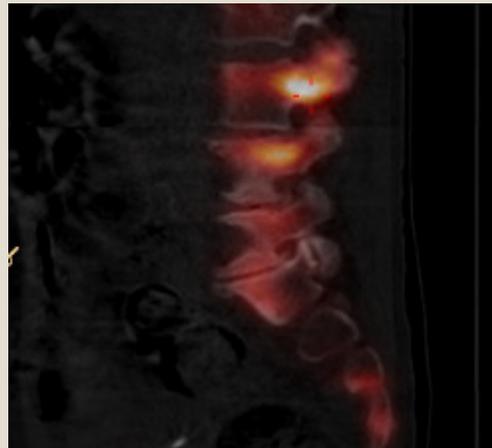
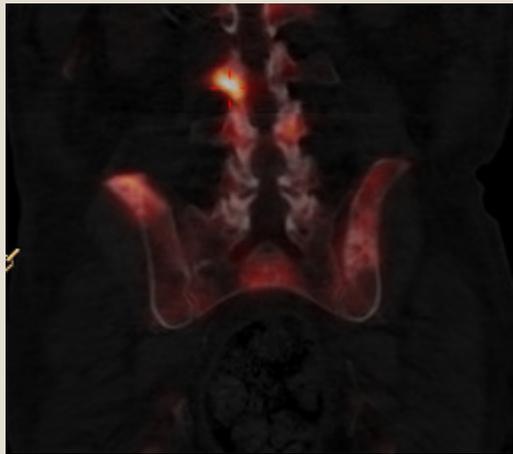
Cognition

Cardio-renal picture

Urea Level



Cancer picture



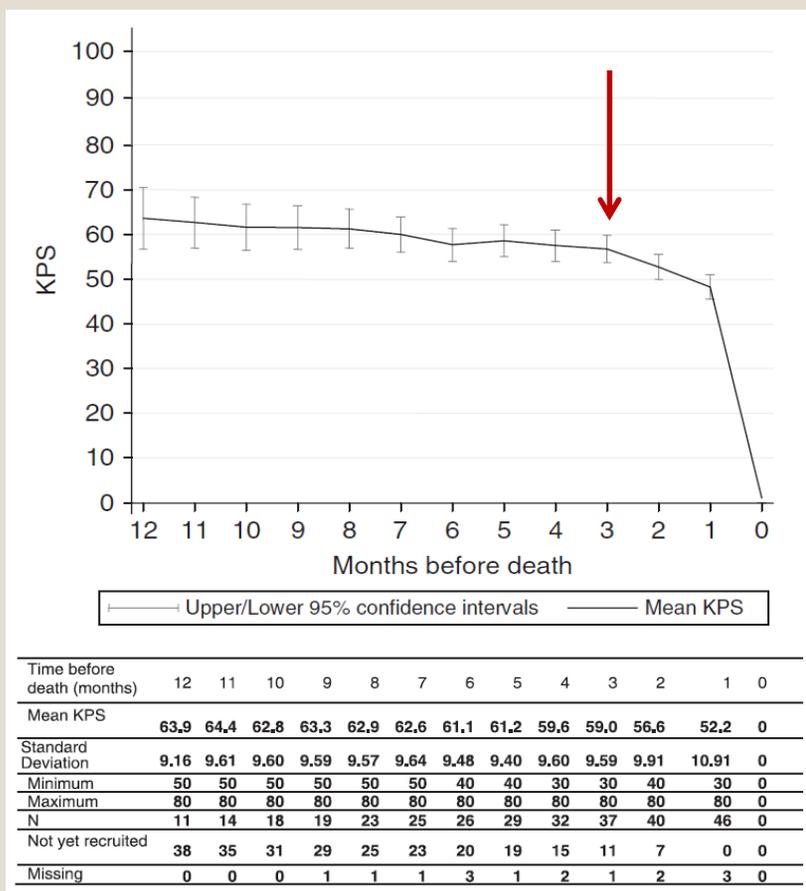
Functional Decline

- Australian-modified Karnofsky Performance Scale (AKPS)

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Decline near end of life

- Functional decline in last 3 months before death
- We see the escalation of family stress
- Struggle to cope in last 2 months
- Potential for admissions due to carer stress and health issues and higher requirement for community resources



End-Stage Renal Disease: A New Trajectory of Functional Decline in the Last Year of Life

Fliss E.M. Murtagh, PhD,* Julia M. Addington-Hall, PhD,† and Irene J. Higginson, PhD*

Common issues / fears

- Aging issues
 - Increasing frailty
 - Mobility issues, continence issues
 - The ageing carer
 - Transport issues, loss of independence, loss of health
 - Financial stress
 - Housing stress (i.e. stairs, public housing)
 - Waiting time for services
 - Inadequate services
 - Cost of continence aids

Common issues / fears

- Health Issues
 - Carer stress (work, financial, own health, other responsibilities)
 - Wish to stay at home for as long as possible
 - Wish to avoid nursing home
 - Fears around discharge planning (can't stay in hospital, don't want NH, too unsafe for home, family friction around going home, rehabilitation issues (no clear goals, more palliative than intensive....))
 - Managing medications (Webster pack)
 - Increasing dementia issues

Common issues / fears

- Nearing End of Life
 - Discussion on where the preferred place is (is it appropriate, crisis planning, discharge planning...)
 - Time based bed pressure in hospital
 - Criteria around hospice
 - Conflict about what can be done and expectations
 - Want to stay in hospital
 - Want 24 nursing care at home
 - Home vs hospital vs hospice
 - Prognosis (dialysis vs non-dialysis)

Important notes

- There is no crisis palliative service for new patients in the community – hence early involvement by us
 - Can't call us when everything has fallen apart and expect someone to home visit that day – even that week!
 - Can't make first assessment on the phone
- Renal failure itself has few symptoms – hence death can occur quickly at the end with no time for home death (organising takes time), and hospitalisation is likely
- Renal patients with low comorbidities on a conservative path rarely meet palliative criteria until they are dying
 - Respite at Hospice admission unlikely – not for aged care needs only, must have a complex symptom burden or be dying

The Carer

- Vitally important in all considerations for care
- Who they are and depth and breadth of role
 - Sometimes they are caring for more than one person
 - Are they the decision maker for medical care if the patient is not able to make decisions?
 - How often are they at the home?
- Forward planning for when things become more difficult
 - What are their wishes for future care, end of life care etc
- Allied health involvement early
 - Dietitian to teach how to cheat with food restrictions
 - Social worker for social/psychosocial assistance
- Respite care

Pre-crisis planning

- What do you expect the issues could be?
 - SOB?
 - Fluid overload?
 - Pain?
 - Profound weakness – cannot perform ADLs
- What is something the family can do at home before things get frantic?
 - How to manage SOB early
 - Daily weigh and a Lasix plan
 - How to use prn medicine and when to call for help
 - Equipment early

Pre-crisis planning

- Encourage family to call early – don't wait until they are already at breaking point
- Remind that there is a waiting time for community services – early referral cannot be underestimated for its value
- Know the goals of care
 - Comfort?
 - Dialysis until the end?
 - NFR?
- Don't make promises you can't keep i.e keeping out of nursing home

Community needs

- Social worker help with getting services
 - Such as.....MyAgedCare (MAC)
- When is community palliative care involved?
 - Dependant on complexity of symptoms or prognosis
 - Know your areas referral criteria and build a rapport with the team
- If only aged care needs, need to follow path of MAC referrals and may need nursing home.



Community resources

- GP
 - Nursing
 - Quick response program
 - Continence
 - Geriatric Flying Squad (nursing homes)
 - Mental Health
 - Palliative
-
- You need to know what is available in your area, referral criteria and guidelines, waiting times, how to escalate (if you can escalate), what they do....

Case

Mr A has a history of severe heart failure and haemodialysis is now impossible due to hypotension and can only be carried out with inotrope support, but he is not for ICU and is unlikely to recover.

- A family meeting is held
- Mr A has been aware for a long time now that this time may come, his family are also very understanding. They are upset, but ask a lot of relevant questions.

Case

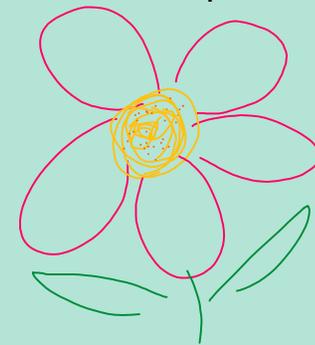
- Family have a choice for preferred place of death
 - Hospital (time likely short – but how short?)
 - Home (need to be willing and able, have a home visiting GP that has known him approx 6 months, have equipment and CPCT in place before discharge)
 - Hospice
 - Nursing home
- What do we need to know as staff?
 - Prognosis (important for planning place of death if likely to be prolonged)
 - What is and is not possible (patient must be safe and cared for)
 - NFR – does everyone know what is happening?

Case

- Home:
 - Equipment (OT)
 - Community palliative care (send home with end of life medicine pack, GP aware and willing to visit and sign death certificate) – may require community medication chart
 - Home O₂ if required
 - Authorised Adult Ambulance Care Plan
- Hospice
 - Book bed with family permission once you know prognosis (may not be appropriate)
 - Daily review until transfer – or change plan to stay in hospital if deteriorates to unconsciousness before bed available

Case

- Hospital
 - Continue palliative pathway – explain everything to family / staff
 - Leave after hours contact in case of distress
- Nursing home
 - If from an aged care facility is a return appropriate? (prognosis is weeks/months) – for permanent residents, hospice is not appropriate here.
 - Send pack of medicines back with the patient and a ‘palliative approach letter’



Basic End of life medicines

- Hydromorphone (2mg/mL ampoule) 0.25-0.5mg SC Q2-4hrly PRN for SOB/pain (if already on regular pain relief change to subcut equivalent dose and make sure there is a breakthrough order also)
- Haloperidol (5mg / 1 mL) 0.5-1mg tds SC PRN for nausea/delirium
- Midazolam (5mg / 1 mL) 2.5-5mg SC Q2-4 hrly PRN for terminal agitation
- Glycopyrrolate (0.2mg/1 mL ampoule) 200-400mcg Q1-2hrly SC PRN for terminal secretions (can increase if very wet and gurgly to 400-800mcg)
- Lorazepam S/L (sublingual) 0.5mg tds PRN for anxiety
- Clonazepam drops (2.5mg / 1 mL) 0.25-0.5 mg S/L (sublingual) bd prn for myoclonic jerks
- Sodibic mouthwash 1% po 10ml QID regular
- Aquaspray po 1 QID regular

End of life medicines – if has Parkinsons or restless leg syndrome

- Hydromorphone (2mg/mL ampoule) 0.25-0.5mg sci Q2-4hrly PRN for SOB/pain
- Glycopyrrolate (0.2mg/1 mL ampoule) 200-400mcg q2hrly sci PRN for terminal secretions
- Midazolam (5mg / 1 mL) 2.5-5mg sci Q2-4 hrly PRN for terminal agitation
- Clonazepam drops (2.5mg / 1 mL) 0.25-0.5 mg S/L (sublingual) bd prn for myoclonic jerks
- Lorazepam S/L (sublingual) 0.5mg bd-tds PRN for anxiety
- Sodibic mouthwash po 10ml QID
- Aquaspray po 1 QID
- Cyclizine 25mg tds sci prn for nausea
- Olanzapine AN ODT 2.5-5mg bd prn for delirium/agitation

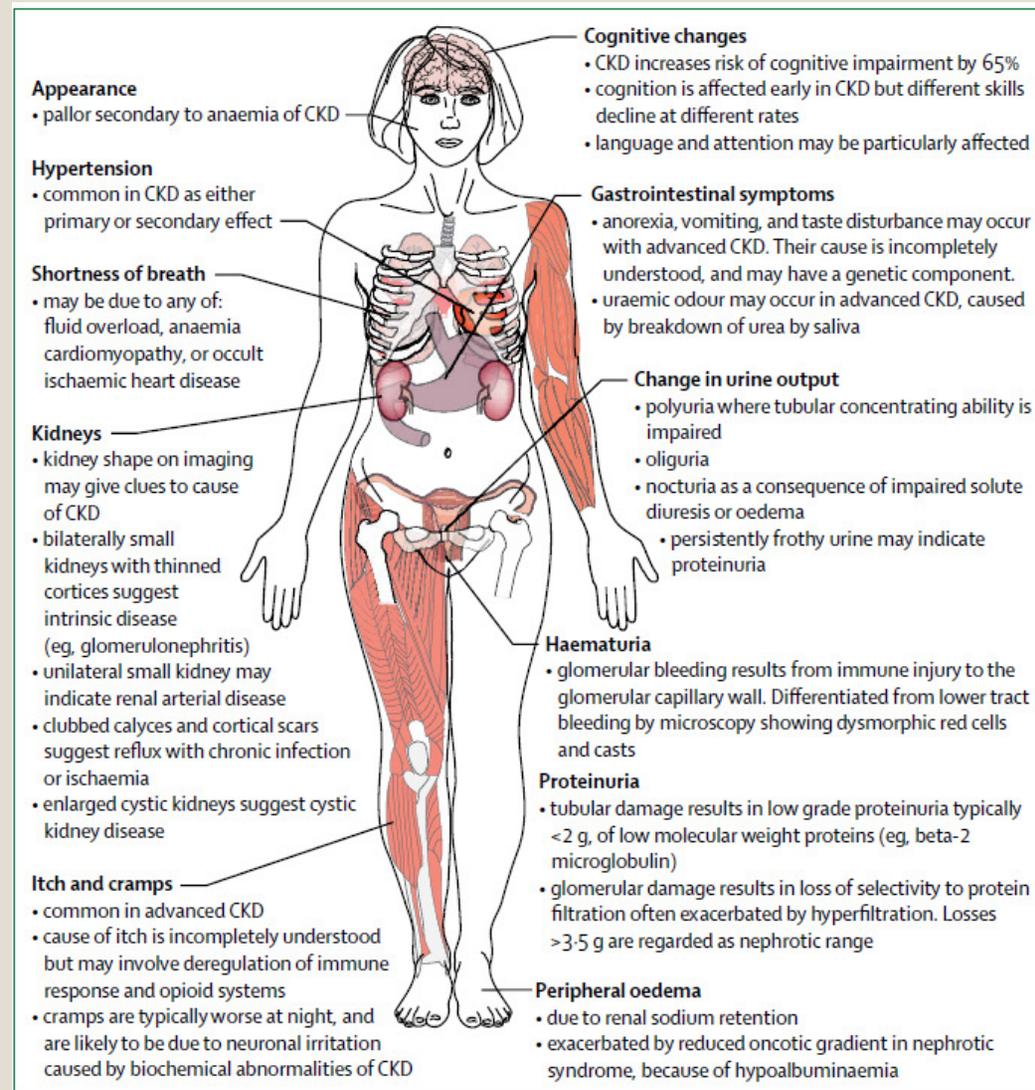
Last 48 hours of life

- For every patient and family, the experience will be different
- Never presume what is the worst thing
- Ongoing assessment



***The family will remember everything – a bad death will be remembered and recounted in the family for a very long time*

Symptoms and signs in CKD



Chronic kidney disease

Angela CWebster, Evi V Nagler, Rachael L Morton, Philip Masson

www.thelancet.com Vol 389 March 25, 2017

Figure 2: Symptoms and signs of CKD



Palliative Approach Letter

Dear Nursing Staff,

The above patient is returning to your facility today. As you can see from the attached discharge summary, the plan is for a palliative approach with no further active treatment.

The St George Renal Supportive Care Team has been involved during this admission, but at time of discharge the patient had no complex symptoms requiring specialist Palliative Care.

As a result I have not made a referral at present to the Calvary Community Palliative Care Team (CPCT).

We have advised the treating team to include PRN medications for potential symptoms as the patient deteriorates. If the patient's symptoms escalate please call the patient's GP. The GP can liaise directly with the Renal Supportive Care CNC or Calvary CPCT for advice if this patient's symptoms are of concern. If the GP is unable to be contacted, please phone Renal Supportive Care or Calvary for advice, mentioning this letter:

Ambulance palliative care plan



NSW Ambulance excellence in care

INSTRUCTION SHEET

Authorised Adult Palliative Care Plan

NSW Ambulance Authorised Care Plans encompass Adult Palliative Care Plans, Paediatric Palliative Care Plans and Authorised Care Plans. It is the responsibility of the treating clinician to ensure all fields are completed prior to submission

SUBMISSION OF AN AUTHORISED CARE PLAN

- The document may be completed electronically and saved utilising a PDF viewer e.g. ADOBE reader.
- Completed forms may be submitted electronically via email: protocolP1@ambulance.nsw.gov.au or fax: (02) 9320 7380
- All fields are to be completed. If handwritten, all fields must be clear and legible.
- Address fields must be complete including post codes.
- Patients with an existing NSW Authorised Care Plan must have 'Existing Patient' checked in the patient details section of the plan.

ENDORSEMENT OF AUTHORISED CARE PLANS

- The treating clinician must approve all authorised care plans by signing the 'Clinician Details' section on page one.
- Adult Palliative Care Plans require authorisation from the patient, where appropriate, in the relevant section on page two
- Adult Palliative Care Plans require endorsement from the patient's family and/or enduring guardian.

ENDORSEMENT BY NSW AMBULANCE

- NSW Ambulance will review and endorse each completed application upon receipt.
- Patients will receive via post a copy of the completed endorsed plan and a covering letter. Please allow up to five business days for receipt. Adult Palliative Care Plans may be sent to either the patient or the family/enduring guardian as nominated in the relevant section of page two. Where no selection is made, the plan will be sent directly to the patient.
- A copy of the completed endorsed plan will be forwarded to the treating clinician via fax or emailed in PDF format where a valid email address has been supplied.
- Incomplete forms may result in processing delays.

MEDICATION ADMINISTRATION

- NSW Ambulance paramedics may administer medications within their specific clinical scope of practice without additional authorisation. Note: not all clinical levels can administer the entire suite of pharmacology.
- Medications outside of the NSW Ambulance clinical pharmacological scope of practice must be available with the patient at all times to enable administration by NSW Ambulance paramedics in accordance with the instructions detailed on the patient's plan.
- The current list of medications available under the NSW Ambulance Clinical Pharmacology (as of July 2015) include: Adrenaline, Amiodarone*, Aspirin, Atropine*, Benzyl Penicillin, Calcium Gluconate*, Clopidogrel, Compound Sodium Lactate, Droperidol, Enoxaparin Sodium, Fentanyl, Fexofenadine, Frusemide, Glucagon, Glucose 10%, Glucose Gel, Glycerol Trinitrate, Ibuprofen, Ipratropium Bromide, Ketamine*, Lignocaine*, Methoxyflurane, Metoclopramide, Midazolam, Morphine, Naloxone, Ondansetron, Oxygen, Paracetamol, Salbutamol, Sodium Bicarbonate*, Tenecteplase (*intensive care paramedics only).
- Unless specified otherwise, paramedics will administer medications in accordance with NSW Ambulance pharmacology.

ENDORSED CARE PLAN EXPIRATION

- All endorsed Authorised Care Plans will remain in effect for a period of 12 months from the date of endorsement unless a reduced review date is requested by the treating clinician.
- It is the responsibility of the treating clinician to review the plan and submit a new plan prior to the 12 month review date.
- In the event the endorsed plan is no longer required, a cancellation notification including the reason for the cancellation should be forwarded to NSW Ambulance via email: protocolP1@ambulance.nsw.gov.au.

HYDRomorphone shortage

- Dilaudid is currently in shortage.
- Limit prescribing to prioritise patients with renal failure
- Morphine is avoided unless there is no alternative available
 - Reduce dose (calculate dose from the renal appropriate HYDRomorphone dose) and time intervals – watch for toxicity
 - Can use Fentanyl (used in Broken Hill)
- If pain is under control, Panadol, Journista, Endone, Oxycotin, Fentanyl patch, Norspan patch, Tramadol
- Avoid NSAIDs

Conclusion

- Dialysis versus non dialysis end of life – increasing frailty in both, end of life medications are the same but always look at co-morbidities and current pharmaceuticals
- Symptoms can be absent until very late, then deterioration occurs quickly
- Community resources – early referral, escalating urgency, carer support paramount
- Good ongoing relationships with your local community resources with ongoing communication
- Treat symptoms to effect and side effect
- Always refer onwards where required
- Avoid conflicting information
- Have clear plans that are easy to follow for the families and teams

References

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