

Care of the dying in End Stage Kidney Disease (ESKD) - Conservative

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Introduction

- What does conservative management look like?
- How does the patient with chronic kidney disease (CKD) decide to have conservative management?
- Management of the renal failure
- What to expect in end stage renal failure
- Case managing
- End of life care



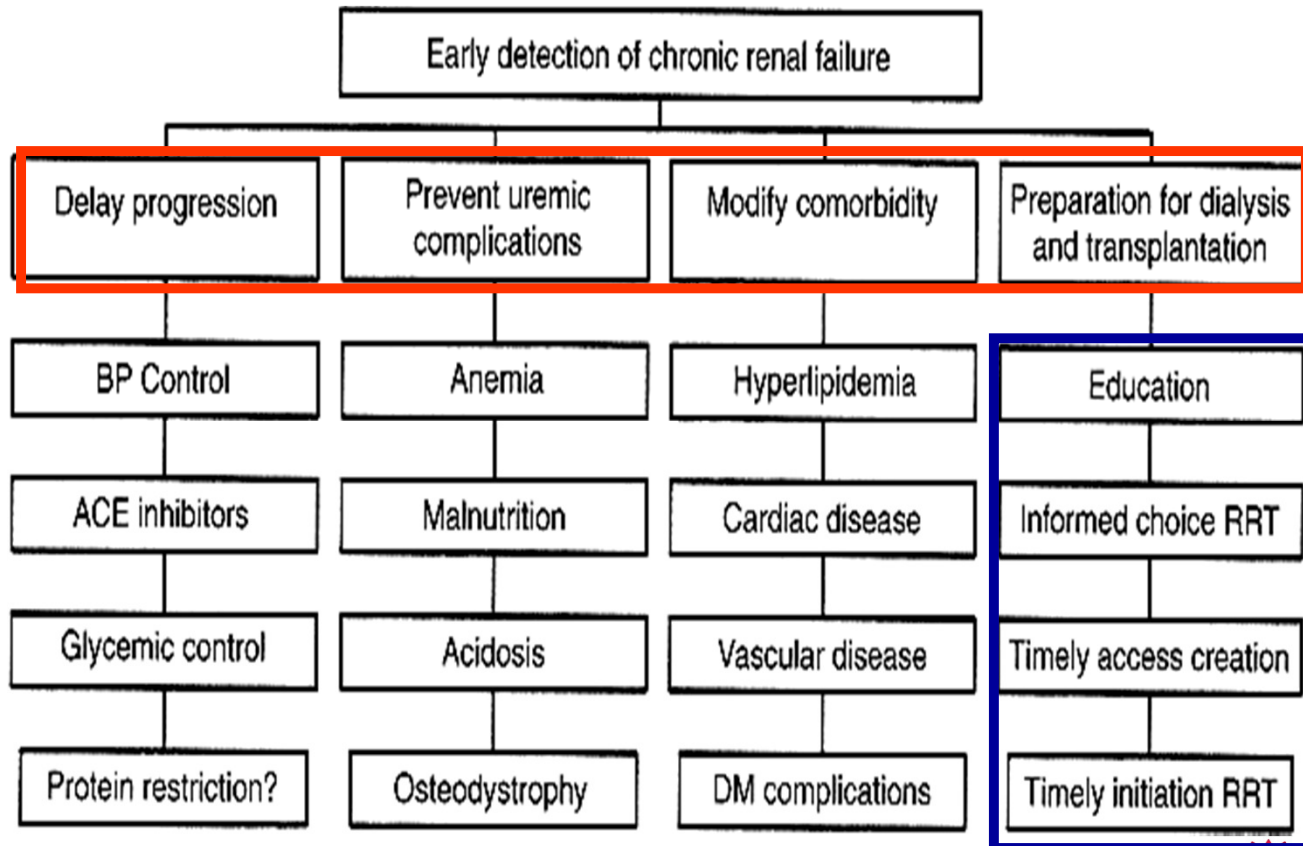
Scenario's

- Conservative managed patient at end of life
 - Aged
 - Those with no other comorbid disease
 - Those with significant other co morbid disease
 - Cases
- The transplant patient



Background to the decision making process in Chronic Kidney Disease

Management of Chronic Renal Failure



Cessation of Dialysis

- The patient has a sentinel event and dialysis is no longer possible
 - ED, ICU, Ward
- The patient is progressively becoming more unstable on dialysis
 - Frequent hypotension (steps already taken to look for reversible causative factors)
 - Dialysis being cut short over a period of time due to hypotension, dementia agitation, on request of the patient due to distress, other medical issues including restless legs until dialysis is not adequate and essentially 'palliative'
- Quality of life of the patient, their decision
- Failed dialysis access, run out of options

Prognosis post dialysis cessation

- Haemodialysis
 - If anuric : 7-10 days
 - If passing urine: time is less clear. Dependant on urine volume, co-morbid disease burden. Could be days, weeks months (182 days)
 - Plans for place of death vary: home, hospice, nursing home
 - Those that survive for months, dealing with disappointment can be an issue (loss of independence, facing nursing home when never wanted)
- Peritoneal Dialysis
 - Time is unknown.
 - Plans need to be realistic for place of care - individual

What conservative management means

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



Conservative: Fine balance of staying well without being over restrictive



Meet Mr. Bates, our perfect patient. He controls his fluid levels by not drinking and his potassium, cholesterol and phosphates by not eating.



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Not going overboard with conservative restrictions



I really feel that you should
start dialysis immediately!



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Conservative – if mainly aged care needs

- Problems associated with aging
 - Increasing frailty
 - Fatigue
 - Decreased mobility
 - Delirium
 - Cognitive decline
 - Requiring higher care needs which the current carer may be struggling with
 - Rate of renal decline is unpredictable for some
 - Look at trend in kidney function and use professional judgement, don't give family a time limit
 - Biochemistry not to be used alone, look at the whole person
 - Managing unrealistic expectations (staying home if care needs cannot be met)
 - Planning ahead for potential problems – case manage



Conservative – if mainly aged care needs

- Deterioration can be very slow.
- Won't meet criteria for hospice admission
- Unclear prognosis
- Aims for care include:
 - Maintain dignity
 - Safe environment (will need services, equipment, nursing homes at times, a carer)
 - Dealing with disappointment (i.e. unable to be cared for at home)
 - Comfort
 - Live life but increase palliative intervention as required



Conservative – if the person has no other comorbid problems other than kidney disease

- Kidney function can be stable for a very long time
 - i.e eGFR 4 for many months
- Look at the trend in renal biochemistry, a fast decline indicates more urgency with preparation for end of life
- No symptoms until last few months
 - Fatigue
 - Sleeping more
 - Itch, myoclonus, anorexia, nausea
- What we see:
 - Sudden decline weeks before end of life
 - Increasing hospital admissions (multiple reasons)
 - Increasing carer stress and acopia
 - Nursing homes sending patients into ED more often



Conservative – if the person has a high co-morbid disease burden

- i.e Cardio-renal failure
- Diabetic complications
 - Peripheral neuropathy
 - Amputations with phantom limb pain
 - Vascular insufficiency
- Cancer diagnosis
- Multi-organ failure
- Cerebrovascular disease

Conservative – if the person has a high co-morbid disease burden

- Death may be from the co-morbid disease
- Prepare early
- Anticipate symptoms
- Work with any other team that may be involved (oncology, vascular, endocrinology, cardiac, neurology etc..)



Case managing the conservative patient

- Know the patient and what specialties they are already linked in to
 - Work with the other services, we don't take over
- Educating families about waiting times for services and letting you know earlier rather than later if services are needed
 - Waiting time for home care services here can be 10-12 months in our area
 - Functional decline to death is around 3 months with eGFR 3-4
- Learn their wishes for place of death
- Know family dynamics and who the main contact person is
- Take part in family meetings if admitted to hospital
 - Meet prior to meeting to ensure MDT knows what is and is not available from palliative services so that nothing is offered that is not actually available to the patient
 - Don't offer false hope – manage expectations



Case managing the conservative elderly patient

- Create a crisis plan for what to do in common anticipated symptom scenario's for that patient
 - We don't have a template as every patient is different
 - Use available community resources from your hospital (you may have a team who goes to nursing homes or patient homes)
- Renal Supportive Care at St George visit nursing homes and inservice staff on end of life care as needed – provide consultative service
- RSC is not a 24 hour service – we need back up plans for out of hours
- May be rare times the conservative patient may need acute dialysis to get them through an acute reversible issue such as #NOF – requires careful discussion



What we find helpful at St George

- Written instructions for family for how to manage symptom flare ups
 - Who to call
 - How to use medications
 - Phone follow up for support
- Use ambulance palliative care plans
 - Can help prevent admissions
 - Ambulance can offer some services in the home (extended care paramedics) without transporting to hospital if that is the wish.
 - Ambulance plans can help prevent opioid toxicity with a list of safe medicine doses
- Collaborating with other community teams

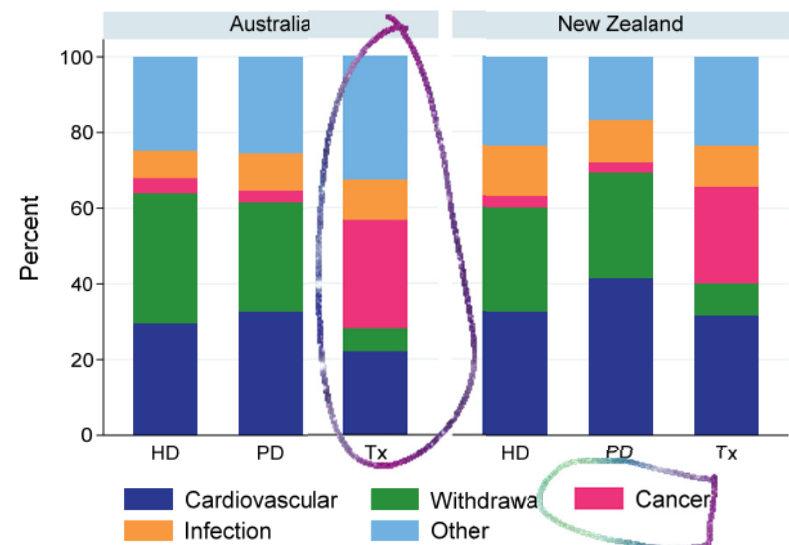
Transplant patient

- End of life care: most common reason for our team is cancer
 - Skin cancers
 - Gastrointestinal cancers (bowel, pancreas, oesophagus...)
- Requires careful shared care with all teams involved to manage the transplant and the symptom management
- End of life care management follows the same principles as any person with CKD, (dependant on level of renal function and pre-existing comorbidities)

Transplant patient

- From The 40th Annual ANZDATA Report (2017)
- Transplant had a cancer rate far above other modalities

Figure 3.5 - Cause of Death - Deaths Occurring During 2016



http://www.anzdata.org.au/v1/report_2017.html



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End of life care

- Anticipatory end of life medications appropriate to the patients needs and co-morbid disease burden
- Rationalise medications to the essentials, mindful we don't want to cause the occurrence of a symptom through medication not given e.g.
 - Anti epileptics, Parkinson's medicines, pain medications
- Comfort eating – mindful of avoiding fluid overload, education to family about risk of aspiration

EOL anticipatory medications

- **Pain:** Hydromorphone starting from 0.25 -0.5mg Q2-4H sci prn – if the patient is already on regular Hydromorphone orally, may need to convert to sci which is half the oral dose.
 - The **breakthrough** dose is calculated in proportion to the background (total daily) dose and is usually **1/12 to 1/6 of the total daily dose given 2/24 PRN.**
- **Agitation** (nausea and delirium): Haloperidol 0.5-1mg bd po/sci. (We have used Haloperidol 1-1.5mg tds sci for severe delirium with a breakthrough dose of 1mg tds sci)

EOL anticipatory medications

- Midazolam 2.5-5mg sci Q2H prn if ongoing agitation
- **Terminal secretions** (Glycopyrrolate 200 – 400mcg q2 –4 hrs sci).
- Lorazepam 0.5-1mg po/sublingual bd-tds for anxiety (important for heart failure where fluid on lungs/ **SOB** causes anxiety)
- **Myoclonic jerks or seizures**, add Clonazepam 0.25-0.5 mg bd sublingual or sci (keep in mind number of benzos the patient is on already). Sublingual solution needs to be ordered from pharmacy.

Levomepromazine (Nozinam)

- Used for:
 - Restlessness, confusion, agitation, nausea
- Requires SAS form from pharmacy for permission to use
- Only used if absolutely required in the terminal phase

EOL anticipatory medications - Notes

- Note: In **Parkinsons** or **Restless Legs Syndrome**, avoid Maxolon, haloperidol (as they are dopamine antagonists).
- Instead use Cyclizine 25mg tds po/sci for nausea and Olanzapine AN ODT (orally disintegrating tablet) 2.5-5mg bd prn for delirium/agitation or use Clonazepam if unconscious. Domperidone 10mg tds for nausea/vomiting.
- Note: In a nursing home situation, if no access to Glycopyrrolate, then use Atropine 1 % eye drops sublingually 2 drops tds and prn 2-4 drops q 4 – 6 hours, or Hyoscine butylbromide (Buscopan) 20mg sci q4 hours and prn q 2- 4 hours



Example of individual care

- Renal failure caused by chronic self harm due to a mental condition
- Assessed and has having capacity to make decisions
- Family have anger due to ‘...caused this’
- Decision ‘not for dialysis’ made clearly by the patient
- Management includes:
 - Regular case conference with entire MDT which the patient knows about and says what they want from the team
 - Support with each decline in renal function
 - Community palliative care helps with chaplaincy support (very helpful)
 - Keeping well, feels supported
 - Plan for the future in all aspects of care



Summary

- End of life can be rapid, but also prolonged
- Don't give a time frame if the patient is passed a lot of urine, rather 'time may be short', we will need to take it day by day
- Rationalise medications appropriately in discussion with family
 - If stopping medications causes family distress, negotiate (usually includes discussion around 'when non longer able to swallow')
- Dealing with bed management if hospice not wanted
- Advocating for single room
- Prepare family for all scenarios (sudden, prolonged, anticipatory medications, what to expect when actively dying)