# Care of the dying patient with ESKD

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The family's view of the manner of dying and the care given will have a major effect on their bereavement and will echo down the years in the way they view death.

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ESKD patients may die :

- Having been on dialysis

- Never having been on dialysis

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## Dialysis patients

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Patients with ESKD on dialysis may die in many different ways.

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1. Sudden death

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## 2. Withdrawal from dialysis

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Withdrawal from dialysis
may come for various reasons.

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1. It is not possible to continue dialysis

Repeated hypotension on dialysis
Vascular Access issues

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2. Patient is struggling with:

*the process of dialysis
*overwhelming symptoms
*other illnesses.

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- George has been on dialysis for 9 months
- He is increasingly fatigued and more frail. No clear reversible cause.
- Further exacerbations of Chronic Airways Limitation.
- Acute Myocardial Infarction
- He presents with a gangrenous toe - post amputation, worsening gangrene… discussion about further amputation.

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J started haemodialysis at age 76 years.

3 years later he is showing signs of dementia.

He struggles on dialysis; the nurses report his behaviour is worsening during dialysis.

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Here a Nephrologist
may respond in various ways.

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# Nephrologist 1

"Its time to talk to him and his family about the future. We need to be honest. It is right to say to him that he could withdraw from dialysis at any time, that would be OK. We would then speak about what to expect from that point onwards including our care for he and his family."

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## Nephrologist 2

"If he brings it up of course I will talk to him…
but only if he raises it. It should come from him."

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## Nephrologist 3

"I think it is time to stop dialysis…
but the family insist I keep going with dialysis…
I will do what the family wants…
I do not want to be sued."

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If the Nephrologist considers that it is time to consider ceasing dialysis then that should be stated clearly.

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Without a clear medical recommendation by the Nephrologist the patient and family drift without direction…

The patient may enter a forest of suffering.

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Professional courage

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In all of these situations the Nephrologist should discuss the possibility of withdrawal from dialysis.

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It is important that any discussion about withdrawal
is open and honest,
at the patient's own pace
and includes the family.

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Common questions…

- How long will I live ?
- What should I expect ?
- Will I drown in fluids ?
- Will I suffer ?

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How long will I live without dialysis ?

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Patients survive a variable time.

- If completely anuric – 7-10 days
- If still passing urine – weeks-months

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Role of culture and religion
in withdrawal decision-making

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Religious and cultural beliefs are intrinsic to us as human beings

and invariably play a role in
difficult decision-making.

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**End of life issues for different religions**

*Lancet* 2005; 366; 682-6

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A consensus across the world's main religions
is that the withdrawal of treatment is
acceptable
if it is in the patient's best interests.

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Culturally there may be significant issues.

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"In our culture, any major decision would be made collectively and together as a family, not simply by the individual."

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"In our culture, stopping treatment means
we have given up and we must be seen to keep fighting."

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Edwina Brown, Nephrologist, London

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"The principles of truth-telling and autonomy are embedded in… Anglo-American ethics.

In contrast, in many parts of the world, the cultural norm is protection of the patient from the truth, decision-making by the family, and a tradition of familial piety, where it is dishonourable not to do as much as possible for parents."

Brown et al. *CJASN* 2016;11:1902-1908.

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3. A dialysis patient has a major sentinel event that is irreversible.

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- A 64 y.o. woman
- Haemodialysis for 6 years.
- Collapses at home.
- Major sepsis - not responding to antibiotics. Patient deteriorating.
- Dialysis due today.
- Some family members want her dialysis to continue.

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Several scenarios may occur.

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# Scenario 1

The major sentinel event occurs …

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- Family prepared for imminent death
- Nephrologist recommends ceasing dialysis.
- Dialysis ceased- “crisis withdrawal”
- Consensus that there will not be an escalation to ICU etc.

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# Scenario 2

The major sentinel event occurs…

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- No discussion about withdrawal
- Waiting approach
- Patient dies on dialysis, the day of dialysis

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The families in these 2 scenarios
will have very different memories of the deaths
of their loved one.

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This scenario is considerably assisted if there the patient has had prior conversations with their Nephrologist including

an Advance Care Plan

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3. Death on a
   conservative, non-dialysis pathway.

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Trajectories of Illness in Stage 5 CKD : A Longitudinal Study of patient symptoms and concerns in the last year of life.

*CJASN* 2011; 6(7): 1580-1590.

Murtagh FE et al.

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## Longitudinal study of conservative stage 5 CKD

- Included patients with Stage 5 Chronic Kidney Disease with definite decision for conservative (non dialysis) management, and with capacity for consent
- 73 participants (response rate 62%)
- 49 (66%) died during follow-up
  - mean age 81 years, range 58-95 yrs
  - 24 (49%) men
  - median follow-up 8 months (range 1-23 months)
- Outcomes measured monthly until death or study end
  - Symptoms (MSAS-SF)
  - Palliative needs (POS)
  - Functional status (KPS)



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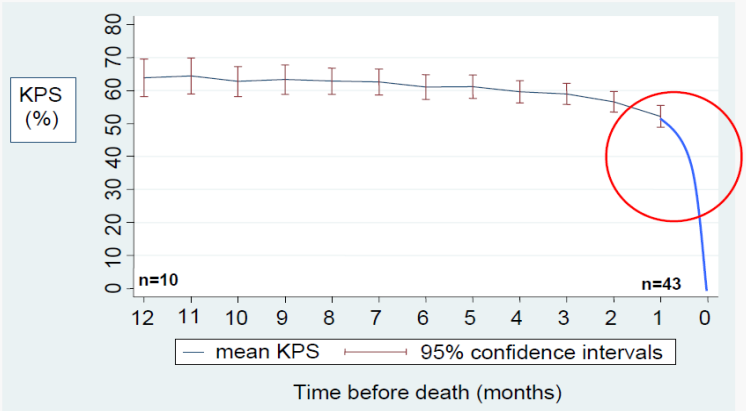
## Trajectory of functional status:



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## Trajectory of symptom distress:


www.kcl.ac.uk/palliative

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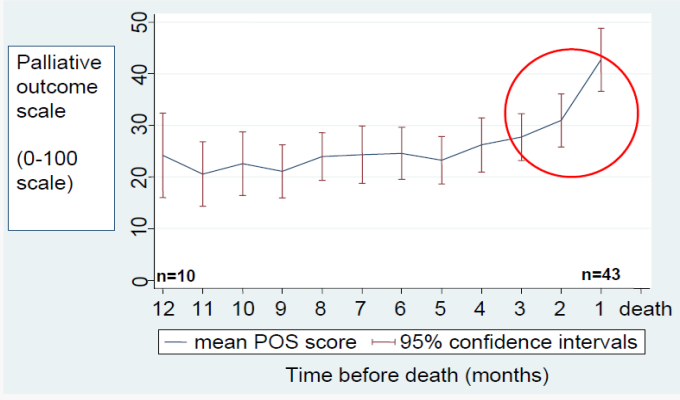
## Trajectory of palliative needs:




www.kcl.ac.uk/palliative

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What are the important things now to think about ?

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Location of care

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Privacy for the family

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Medical care

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Nursing care

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Spiritual care

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Barriers to diagnosing dying

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Men fear death
as children fear the dark;
and as that natural fear in children is
increased with tales,
so is the other.

Francis Bacon

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"No need to be so scared of words, doctor. This is called dying."

LUIGI PIRANDELLO, writer, on his death-bed (1936)

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## Barriers to diagnosing dying

- Hope that the patient will improve.
- No definitive diagnosis.
- Pursuit of unrealistic or futile interventions.
- Disagreement about the patients condition.
- Failure to recognise key symptoms and signs.
- Concerns about withdrawing or withholding treatment.

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- Inadequate knowledge of end-of-life medications and the treatment of a dying patient.
- Poor ability to communicate with the patient and family.
- Concern about resuscitation.
- Cultural and spiritual barriers.
- Medicolegal issues.

Ellershaw J and Ward C *BMJ* 2003 ; 326.

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"I'm sorry there is nothing more we can do"

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# The Terminal Phase

FOR THE PATIENT :

1. Comfortable bed, pressure mattress.

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2. Cease unnecessary medications.

One approach in ESKD patients is to continue certain medications as long as possible :

Anti-anginals

Diuretics

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3. Ceasing unnecessary observations

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4. Cease unnecessary investigations

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5. If patient is not swallowing, cease orals and use sci medications.
   Consider converting all necessary medications into a syringe driver.

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6. Mouth care –
   moist mouth – water spray; cotton wool sticks dipped in water.

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7. Indwelling Catheter

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8. Symptom management.

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Symptom management for the adult patient dying with advanced chronic kidney disease: A review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus Group

Claire Douglas et al.

*Palliative Medicine* 2009; 23: 103-110.

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A. Anticipate and manage the general symptoms of dying.

B. Anticipate and manage uraemic symptoms.

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**A. Anticipate and manage the general symptoms of dying.**

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# The Terminal Phase

Pain – use sci opioids (avoid morphine)

Look carefully for signs of discomfort on moving and turning.

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Agitation/restlessness – “Terminal agitation” –
sci Midazolam, intermittently or in a Syringe driver.

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Terminal secretions – can be very
distressing to the relatives

Re-position the patient
Buscopan
Glycopyronium

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## B. Anticipate and manage uraemic symptoms.

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**Uraemic encephalopathy**

Drowsiness → Coma
Delirium
Uraemic jerks

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Delirium – may worsen terminal agitation

- Haloperidol
- Midazalom

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Uraemic jerks –

Clonazepam drops sublingually or Midazolam

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Nausea

Metoclopramide
Haloperidol
Cyclizine

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Pruritus

• While swallowing – oral medications.

• If no longer swallowing –
Lignocaine 200mg sci in a S/Driver over 24 hours.

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# Terminal Phase

FOR THE FAMILY:

Ensure there is an open comforting environment for the family.

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PHYSICAL ENVIRONMENT :

1. Single room
2. Stretcher bed
3. 24 hour access
4. Access to children.
5. Familiar photos/art/music
6. Garden

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If I had but two loaves of bread I would sell one and buy hyacinths, for they would feed my soul.

Sheikh Muslih-al Din Sadi, 13th century Persian poet.

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# Terminal Phase

EMOTIONAL SUPPORT

1. Meticulous communication

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# Terminal Phase

EMOTIONAL SUPPORT

2. Physical care of themselves – “Are you eating ? Are you sleeping ?…Everyday take a break…You are each other’s greatest allies. Look after each other.”

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EMOTIONAL SUPPORT

3. Emotional /spiritual counseling

4. Religion – Priest/Minister/Imam/Rabbi

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## Communication

The importance of good communication throughout cannot be overestimated.

Statements made, asides given, even the demeanor of the health professionals will be remembered and talked about for years to come.

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# For ourselves as Health Professionals

- Need to acknowledge the cumulative effect of our work on ourselves.
- Need to take care of ourselves and each other.

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"I thought there was nothing more
I could offer."

Nephrologist

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*I walked a mile with pleasure*
*She chatted all the way,*
*And left me none the wiser,*
*For all she had to say.*

*I walked a mile with Sorrow,*
*and not a word said she,*
*But oh, the things I learned from her,*
*When Sorrow walked with me.*

Robert Browning Hamilton

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# DEATH

Importance for time to be alone with the loved one.

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## THE FUNERAL

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Respect for the body

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In our sleep, pain which cannot forget
falls drop by drop upon the heart until,
in our own despair, against our will,
comes wisdom through the awful grace
of God.

Aeschylus - Athenian playwright, 5th century BC

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