

# PALLIATIVE PERITONEAL DIALYSIS

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# CASE ONE

- 75 year old woman with baseline CKD IV (Cr 200) and recently diagnosed gastric carcinoma – inoperable and no chemotherapy indicated
- Patient took unidentified alternative medical treatment
- Renal function decompensated with Cr 800

# CASE ONE

- Patient deferred all decisions to very vocal sons and daughter
- Family were not ready for her death and despite skepticism about conventional medicine wanted dialysis
- They chose HD but wanted comfort for mother as a priority

# CASE ONE

- HD initiated via “Permcath” with no plan for fistula
- 3 hours 3 times a week
- Chronic ankle swelling but early attempts at fluid removal caused leg cramps and post HD weakness

# CASE ONE

## Palliative Dialysis begins

- Appetite poor, weight gains minimal and patient refused fluid removal
- Some nurses and residents uncomfortable so palliative dialysis approach defined in patient orders
- No P binders, No BP meds or statins
- Liberal use of anxiolytic meds and opiates for any pain

# CASE ONE

## Palliative Dialysis

- Family sit with patient through every dialysis and say patient finds last 30 minutes very unpleasant
- Time reduced to 2.5 hours, PRU still c 65%
- After 4 mths, family request 2 HD per week
- 2 weeks later, requested resumption of 3 HD per week due to patient feeling less well

# CASE ONE

## The End

- Patient required transfusion for symptomatic ESA resistant anemia
- Discontinuation revisited at intervals but not aggressively and always politely refused
- Gradual weight loss and functional decline
- Patient died at home after 10 months on HD
- Family thanked HD team for care



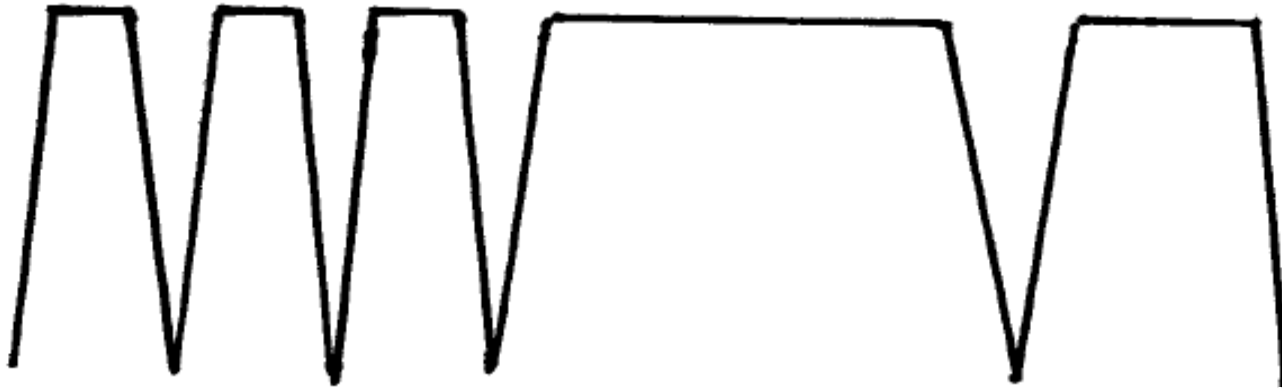


## CASE TWO

- 80 year old woman has diabetic ESRD on APD 3 x 2 L + 2 L day dwell + 2L dwell each evening x 2 years
- Worsening heart failure, hypotension and progressively deteriorating health, losing vision and hearing
- Quality of life is poor according to patient and PD is very hard work

# FREQUENCY CYCLING WITH 2 DAY DWELLS

$$3 \times 2L + 2L + 2L$$



Kt/V 1.75/week, Anuric

# CASE TWO

- You discuss discontinuation of dialysis but patient says her family – husband and 2 daughters would be very upset – and she was not ready for this
- Could she have less dialysis and skip a few days a week?

# CASE TWO

## Options

1. No. If you are not discontinuing you need full prescription PD
2. Insist on patient discontinuing dialysis
3. Reduce PD prescription and allow her skip a few days a week

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# CASE THREE

- 78 year old man with diabetic ESRD and CHF living 3 hours drive from PD unit
- Starts APD 1.9 L x 5 + 1.5 L Icodextrin day dwell
- Initially does well, lots of family support, good Kt/V, stable volume status
- Then has arrhythmias requiring cardioversion and then fluid retention, hypotension, fatigue, ESA resistant anemia

# CASE THREE

## Decline

- 9 months post initiation, exhausted and mostly in bed, low BP, chronic back pain and fear of falls
- Does not want to come to clinic any more but also does not yet want to stop dialysis though family say they will support him if he does
- Last Kt/V 1.59 but not able to repeat
- Wants day dwell reduced due to back pain

# CASE THREE

## Palliative PD x 6 months

- Home care nurses visit daily – continues insulin and laxatives
- PD nurses visit and support by phone but no clinic visits or blood work
- Tylenol for back pain – refuses opiates
- Day dwell discontinued
- Binders and beta blocker reduced and stopped



# CASE THREE

## The End

- After 15 months he refuses further dialysis
- Family and patient and family doctor decide to admit him to local hospital
- Treated with hydromorphone and dies within 4 days
- Family thank PD unit for 15 months of support

# BACKGROUND

- Patient centered care is a priority
- Not all dialysis patients are the same
- Dialysis use has grown worldwide and older, frailer and sicker patients are receiving it
- Some of these patients have very short life expectancy and poor quality of life

# BACKGROUND

- Many of these patients say they regret choosing to start dialysis (Davison CJASN 2010)
- The frail elderly have little or no survival advantage on dialysis
- However, many still chose to do dialysis for many reasons

# Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease

**Jamilla A Hussain** *Leeds Teaching Hospitals NHS Trust, Leeds, UK*

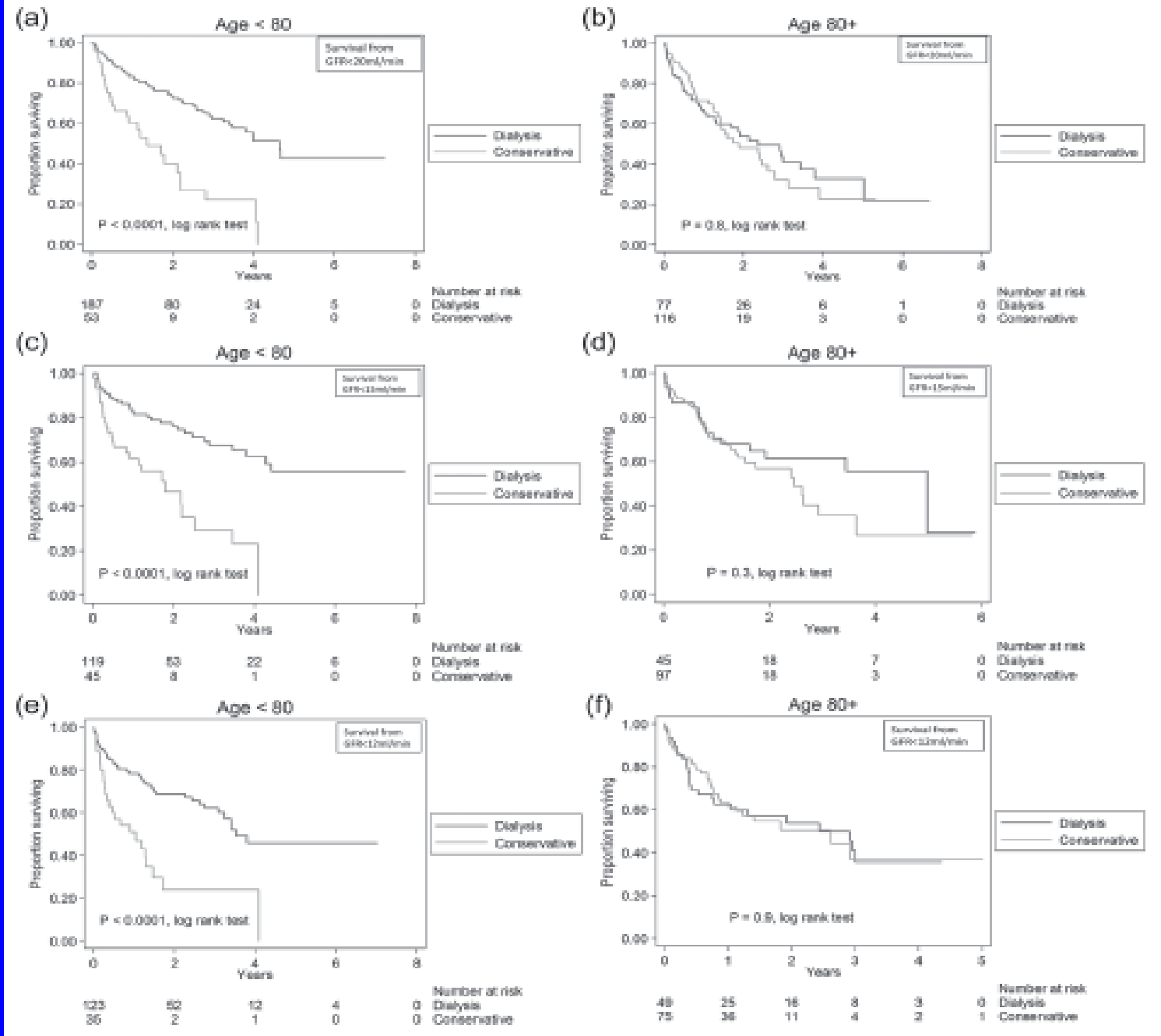
**Andrew Mooney** *Renal Unit Leeds Teaching Hospitals NHS Trust, Leeds, UK*

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# Survival Analysis: Dialysis vs Conservative Care

Hussein et al  
Palliative Med  
2013



# WHY DO FRAIL ELDERLY DO DIALYSIS?

- Never given a choice not to by physicians
- No clear prognostic information given
- Pressure from relatives – spouses, children, parents
- Fear that is against their religion
- Fear of death

# WHY DO FRAIL ELDERLY DO DIALYSIS?

- Others become frail after starting dialysis
- It is often even harder to discontinue dialysis than not to start it in the first place
- Frail elderly continue doing dialysis for same reasons frail elderly start it

# WHAT HAPPENS NEXT?

- The frail elderly often find dialysis very hard with little relief of symptoms
- Some do quite well for a while
- Some deteriorate and die soon
- Some discontinue dialysis
- Some continue to suffer but are afraid to discontinue



# PALLIATIVE DIALYSIS

- This is a proposed approach to the frail dying patient who does not feel able to discontinue dialysis
- Palliative Dialysis is dialysis where the over-riding aim is patient comfort even at the expense of medium and long term outcomes

# PALLIATIVE DIALYSIS

- Low intensity dialysis – might be HD x 2 a week with less fluid off or 'day dry' APD
- Ignores clearance targets or volume status and concentrates on quality of life and symptom burden
- Alternative to stopping dialysis for those not quite ready or able

# PALLIATIVE DIALYSIS

- Very little published on this
- Grubbs et al for ASN Dialysis Advisory Group. A palliative approach to dialysis care. CJASN 2014 9:2203
- Davison S, Jassal SV, Supportive Care...CJASN 2016 11:1882

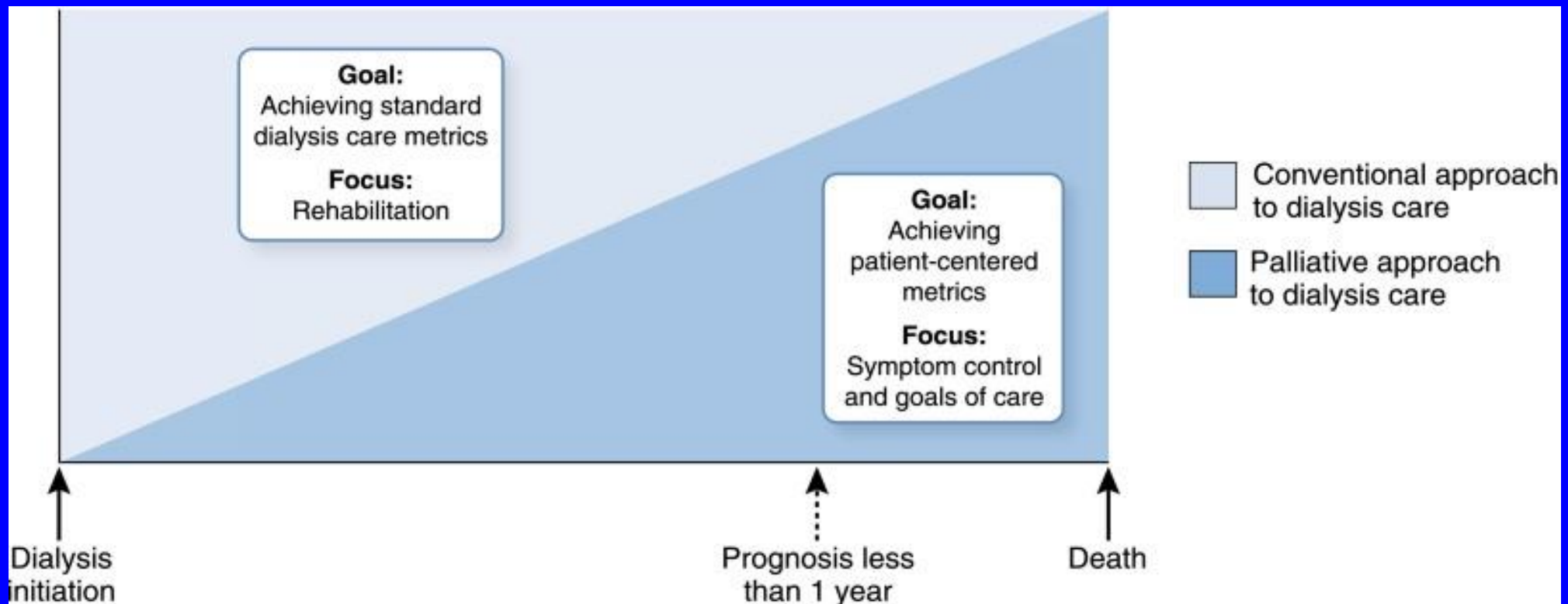
# A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life

Vanessa Grubbs, Alvin H. Moss, Lewis M. Cohen,<sup>§</sup>  
Michael J. Fischer, Michael J. Germain, S. Vanita Jassal,  
Jeffrey Perl, Daniel E. Weiner, and Rajnish Mehrotra on  
behalf of the Dialysis Advisory Group of the American  
Society of Nephrology

CJASN 2014 9 :2203

# Transition to Palliative Dialysis

Grubbs et al CJASN 2014



# PALLIATIVE DIALYSIS CANDIDATES

- Elderly frail patients
- Patients with terminal cardiac failure or malignancy or cachexia
- Anyone with life expectancy < 2 years
- There is a spectrum from those dying rapidly to those dying slowly
- May be 10-20% of patients on dialysis

# PALLIATIVE DIALYSIS

## Priorities

- Symptom management – pain, cramps, restless legs, fatigue
- Avoid uncomfortable investigations
- Avoid most preventive medications
- Multidisciplinary care
- Do not waste patient's remaining time

# PALLIATIVE DIALYSIS

## Role of Palliative Services

- Great if available
- Palliative care physicians
- Palliative Home Care
- Available to patients still on dialysis?



# PALLIATIVE DIALYSIS

## Avoid....

- Worrying about Kt/V
- Giving aggressive onerous PD prescriptions
- Focusing on phosphate and binders – but avoid itch!
- Focusing on volume status high BP and uncomfortable fluid removal

# TWO APPROACHES

## Conventional v Palliative Dialysis

	Conventional	Palliative
Vascular access	AVF or AVG	CVC fine
Kt/V	Follow	Titrate to comfort
CV risk	Treat risk factors	High BP only
MBD	Manage PO <sub>4</sub> , PTH	Titrate to comfort
Diet	Conventional	Minimal restriction
Labs	Regular	As required

Adapted from Grubbs et al CJASN 2014

# VOLUME MANAGEMENT IN PALLIATIVE PERITONEAL DIALYSIS

- Complex issue in palliative HD patients but easier in PD
- Too little fluid off may cause high BP, edema, cardiac morbidity, even pulmonary edema
- Too much may cause cramps, loss of urine, low BP, unpleasant symptoms
- In practice , weight gains are usually small

# PALLIATIVE PD

## SPECIFIC PD ISSUES

Easier to reduce PD dose than HD dose in a patient friendly manner

Removing fluid is gentler and easier in this context

It is OK to die on PD – do not transfer dying people to HD

# PALLIATIVE DIALYSIS ISSUES

## Challenges

- Discomfort of some nurses and residents – ‘either do proper dialysis or discontinue!’
- Ethics of ‘inadequate dialysis’
- Is death by under-dialysis killing patient ?  
But patient is dying anyway
- Waste of public health care dollars?

# PALLIATIVE DIALYSIS ISSUES

## Responses

- It is patient centered customized care
- Not everyone is ready to stop dialysis and die even if their prognosis is poor
- It is no longer ethical to stop dialysis without consent and transparency
- Both these patients had a good death, supported by family and dialysis team

# PALLIATIVE DIALYSIS

## Discussions

- Listen to patient and to family
- Talk to patient and family honestly but sensitively about their prognosis
- Remember family and patient may not be on “same page”
- Family may need separate less subtle conversation re prognosis

# DISCUSSIONS WITH DYING PATIENTS

- Honesty and disclosure critical to therapeutic doctor patient relationship
- However, some patients make clear they do not want to discuss end of life
- Some families try to block this also but family do not always know what patient really wants and may need help too



# DISCUSSIONS WITH DYING PATIENTS

- Do not tell lies to patient – no matter how well intentioned it erodes a central relationship
- Give lots of opportunities for discussion of end of life issues but do not force issue if lead not taken by patient
- If opportunity arises tell truth gently and avoid unjustified certainty

# DISCUSSIONS WITH DYING PATIENTS

- First, offer option of discontinuation to patient and inform close family and revisit a decision to continue at appropriate intervals
- Do so kindly and gently
- If discontinuation refused look for consent for a palliative dialysis approach
- Accept implicit consent if explicit not possible

# DISCUSSIONS WITH DYING PATIENTS

- Do not extinguish patient's hope even if it is misguided
- Dogmatic predictions are often wrong
- Talk and listen and tell full truth but do not argue

# FRAILITY

- Very common in dialysis units
- Various definitions – Fried, Rockwood
- Frailty scores and scales help assessment and understanding and predict survival

## Clinical Frailty Scale



**1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



**2 Well** – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.



**3 Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.



**4 Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.



**5 Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



**6 Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



**7 Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



**8 Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



**9 Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

### Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

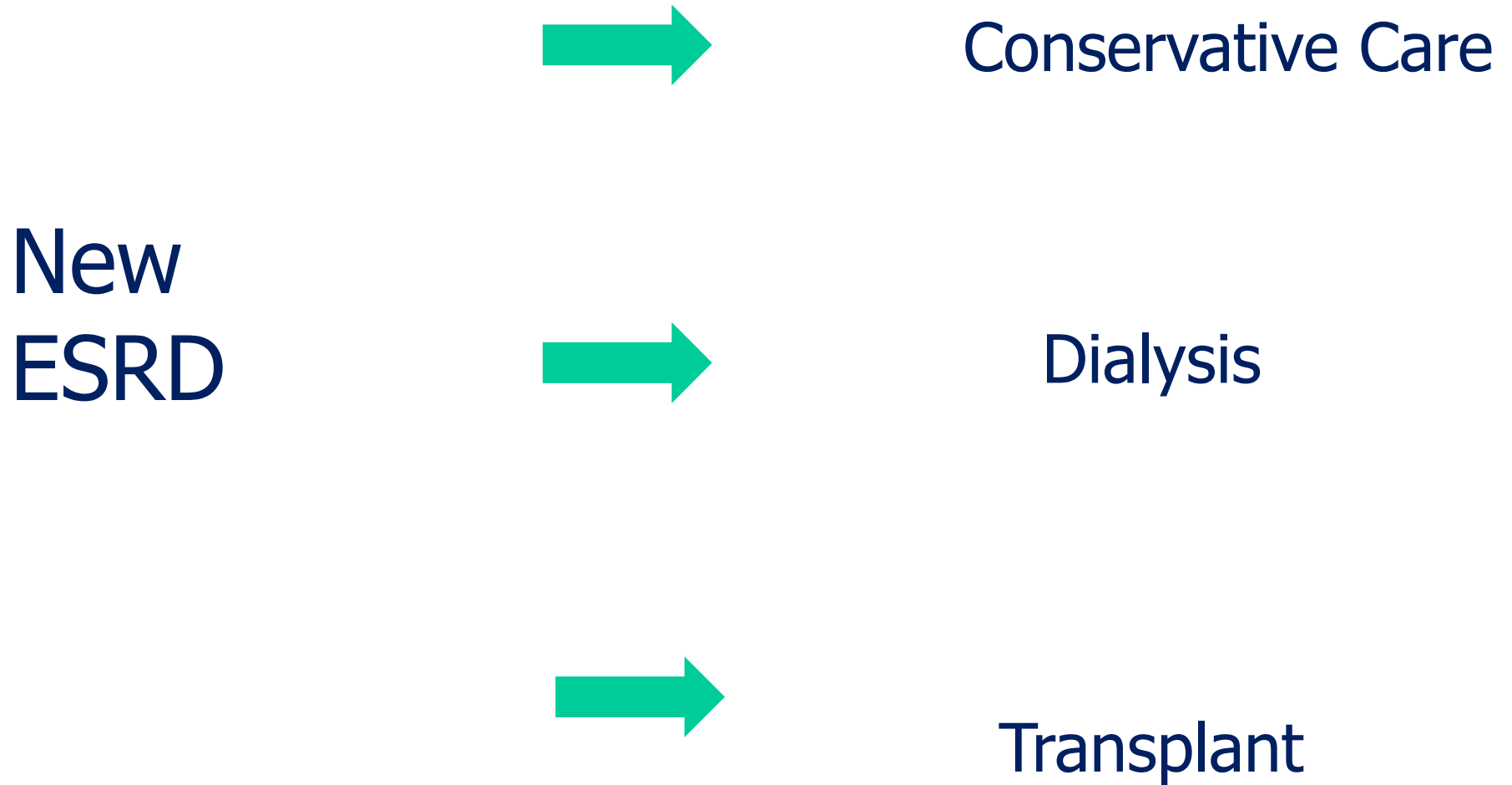
In **severe dementia**, they cannot do personal care without help.

# PALLIATIVE DIALYSIS

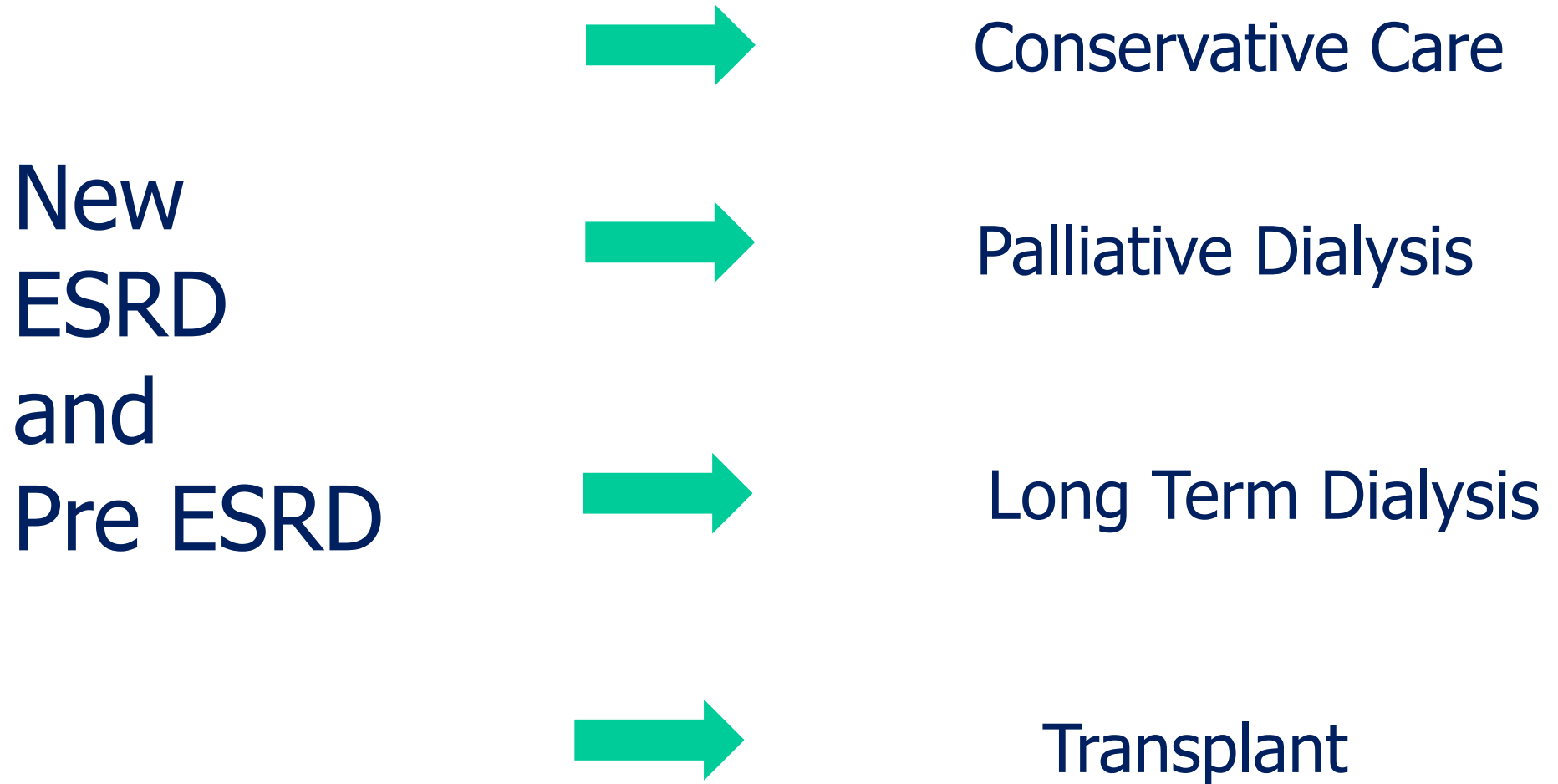
As Nephrologists, we need to understand better...

- Frailty as a concept
- Prognosis and predictors of decline and death
- The language and meaning of palliative or supportive care, of goals of care
- How to address all this in clinical care
- Patient Trajectories in ESRD

# Three Trajectories for ESRD



# Four Trajectories for ESRD



Many patients will switch trajectories during ESRD course



