# Conservative Care Nephrology

OLTCC WORKSHOP, 2022

# Who we are….

Steve Gobran (NP)

Michael Wang (Nephrologist)

# Conflicts of Interest

- Received honoraria from Otsuka Canada Pharmaceutical Inc. for Tolvptan (*Jinarc*) and Patiromer (*Veltassa*) for presentations and drug advisory participation
- These products will not be discussed in today's workshop

# OBJECTIVES

- Brief review of CKD
- What is conservative renal care and why is it important?
- Pillars of conservative renal care:
  - **Clinical management** – symptoms; risk mitigation
  - **Goals of care discussion** – relationship building; advanced care directives
  - **Patient & family support** – community support; grief and loss
- Discussion how we can work together to achieve effective conservative renal care for LTC patients

# Case #1

- 50M resides from LTC on a dementia unit
- From Vietnam and English is not his first language
- No family members in Canada
- Patient does verbalize but limited secondary to ischemic stroke
- Dependent for ADLs and IADLs
- Constant observation due to history of aggression
- Currently voids via foley catheter

# Case #1

- **PMHx**
  - HTN
  - CKD
  - BPH
  - DM2
  - Retinal detachment
  - Prior GIB

**MEDS**

- Vitamin D 1000 units daily
- Clonazepam 0.5 mg 1 tab BID & additional 0.5 mg PRN
- Haldol 2 mg PRN
- Hydromorphone 1 mg q2h prn
- Melatonin 9 mg qhs
- Methotrimeprazine 25 mg q6h prn
- Olanzapine 10 mg qhs
- Senna 2 tabs bid
- Trazodone 50 mg po in the evening then 125 mg qhs
- Trazodone 25 mg po tid prn

# LAB WORK

- Cr 921 (eGFR 5); Urea 37.5
- Na 138, K 4.9, Bicarb 23
- Hgb 89, WBC 13.5
- TSAT 21%, Iron 10, Ferritin 170
- Ca 1.74, Phos 2.80
- Albumin 38

# Clinical Assessment

- Patient alert but not oriented x2, responds to name
- Appears thin and frail, no restless legs noted
- BP: 130/80 P:78
- Lungs: clear, with no adventitious sounds heard
- Heart: S1-S2 heard with no clicks or murmurs
- Abdomen: soft and non-tender, bowel sounds heard in all 4 quad
- Edema: none present

# CASE #2

- 96F from RH with assisted living
- Previously independent before transitioning into her new home
- Uses a walker for mobility and independent with ADLs and IADLs
- Recent fall – hip # → assisted living
- Now admitted to hospital for acute pancreatitis / gallstones: treated conservatively, but high likelihood of recurrence

# Case #2

- **PMHx**
  - Anemia
  - Atrial flutter
  - CHF
  - CKD
  - Chronic myeloid leukemia
  - Gastric cancer
  - HTN
  - Hypothyroidism

**MEDS**

- Tylenol 500 mg po qhs
- Amlodipine 5 mg daily
- Bisoprolol 5 mg daily
- Dasatinib 50 mg daily
- Lasix 40 mg daily
- Kayexalate 15 grams po q2d
- Pantoprazole 40 mg daily
- Synthroid 75 mcg daily
- Vitamin D 1000 units daily

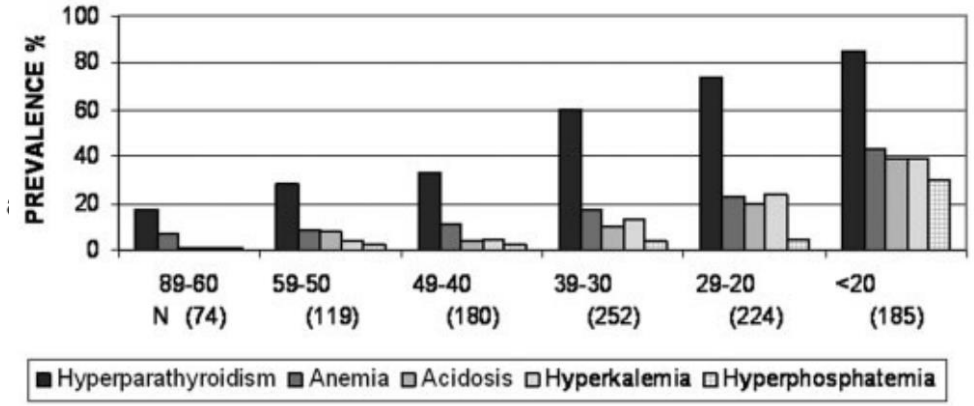
# LAB WORK

- Cr 317, eGFR 10, Urea 35.4
- Hgb 99; WBC 5.0; Platelets 229
- TSAT 24%, Iron 12, Ferritin 882
- Na 140, K 4.9, Bicarb 15
- Ca 2.34, Phos 1.62
- Albumin 45
- ACR 142.6

# Clinical Assessment

- Patient looks of stated age
- BP: 118/46 P:70
- Heart sounds: S1 S2 heard with no clicks or murmurs
- Lung sounds: clear  with no adventitious sounds
- Abdomen: Soft and non-tender, bowel sounds heard in all 4 quad
- Edema: 1+ edema bilaterally along ankles

# REVIEW OF CKD




| GFR categories (ml/min/ 1.73 m$^2$) Description and range | | | |
|---|---|---|---|
| | G1 | Normal or high | ≥90 |
| | G2 | Mildly decreased | 60-89 |
| | G3a | Mildly to moderately decreased | 45-59 |
| | G3b | Moderately to severely decreased | 30-44 |
| | G4 | Severely decreased | 15-29 |
| | G5 | Kidney failure | <15 |

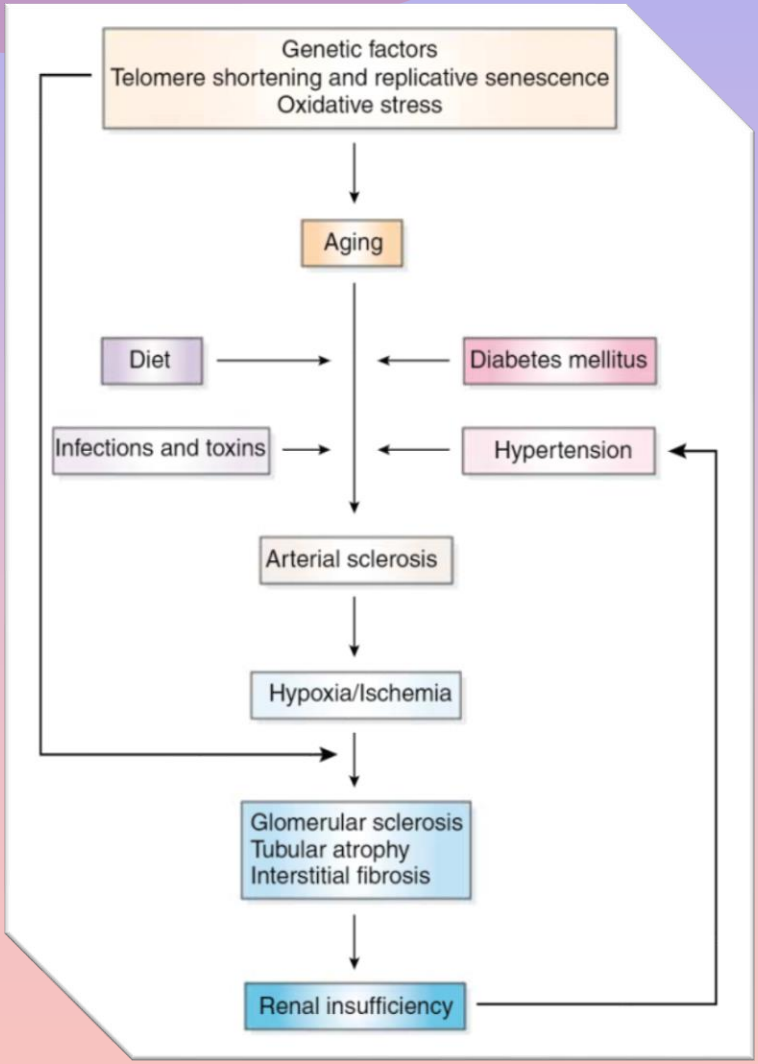
**Asymptomatic**

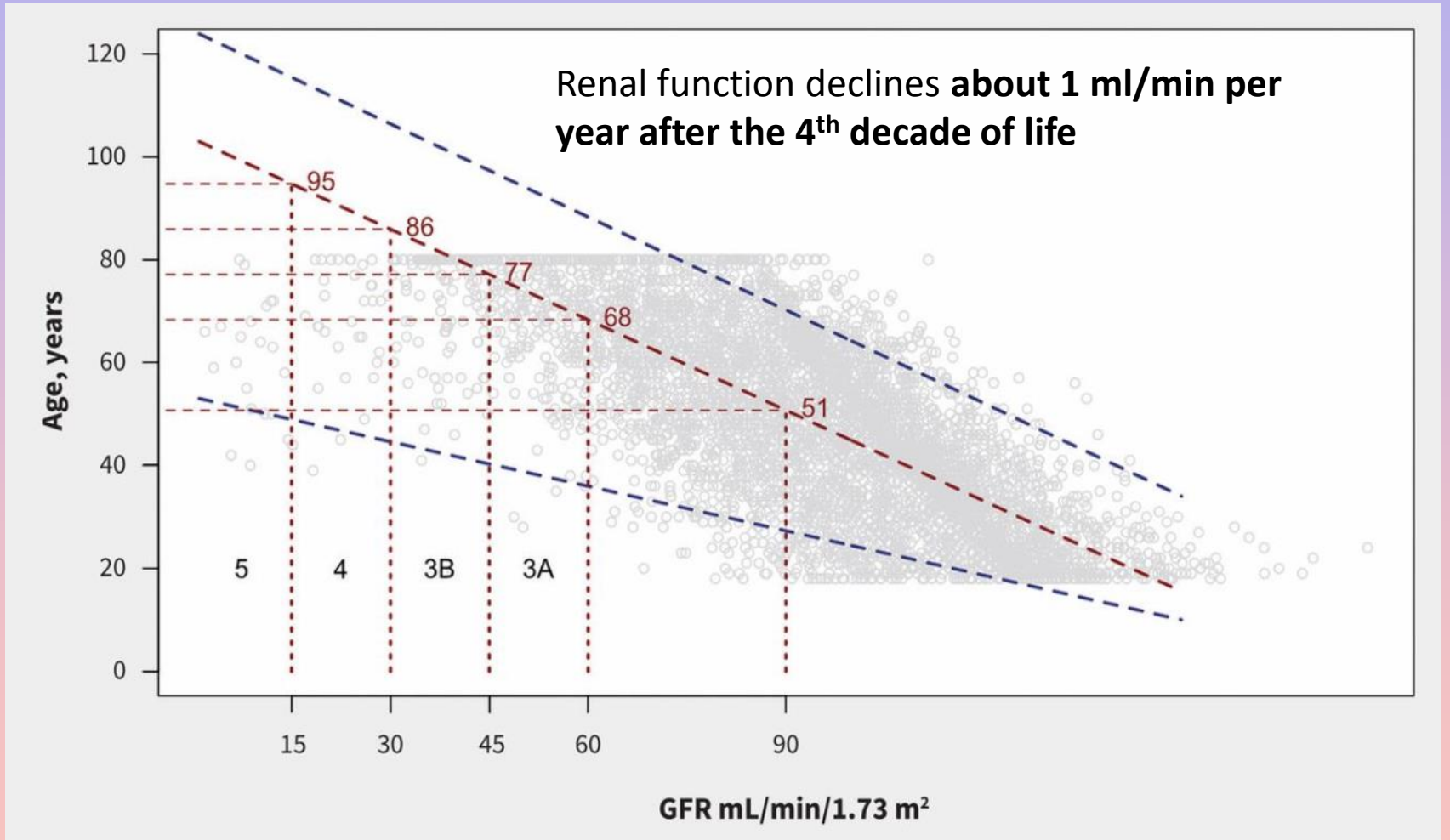
**Metabolic abnormalities**

- Hyper-PTH
- Anemia
- Electrolyte: hyper-K, met acidosis

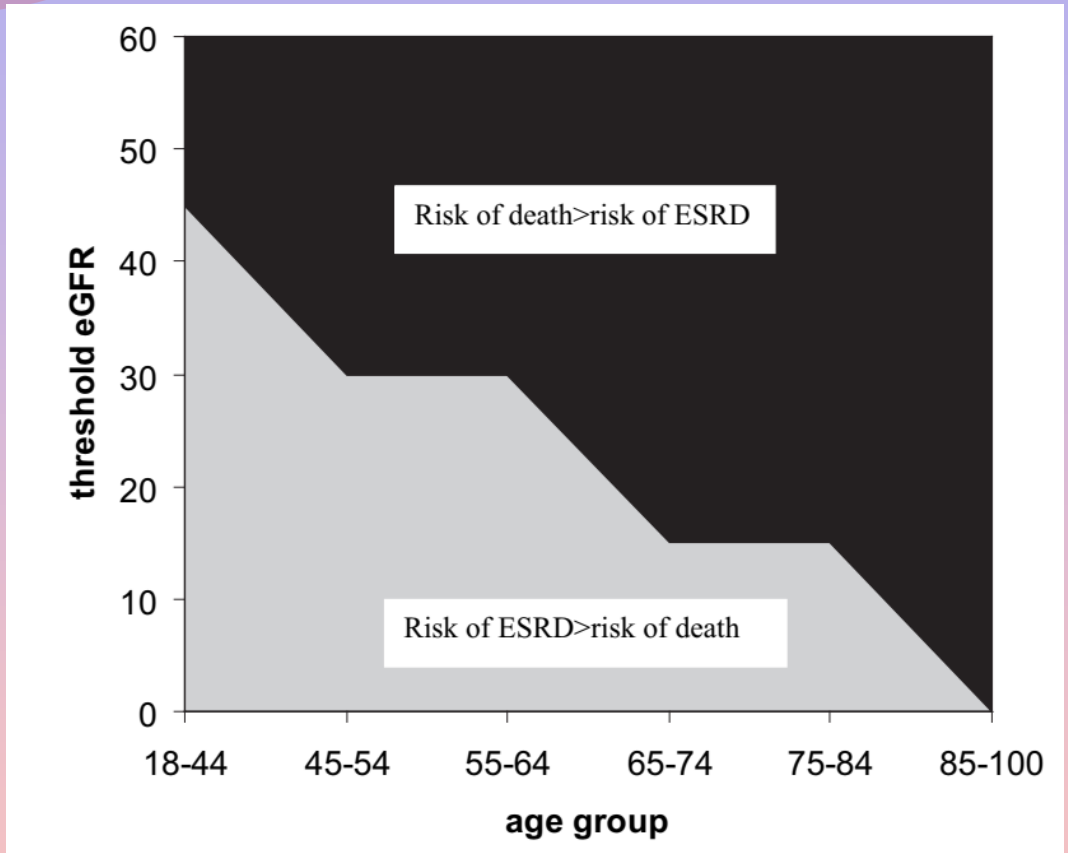
**Uremia***

# The useful concept of Kidney Age



# Kidneys outliving the patient



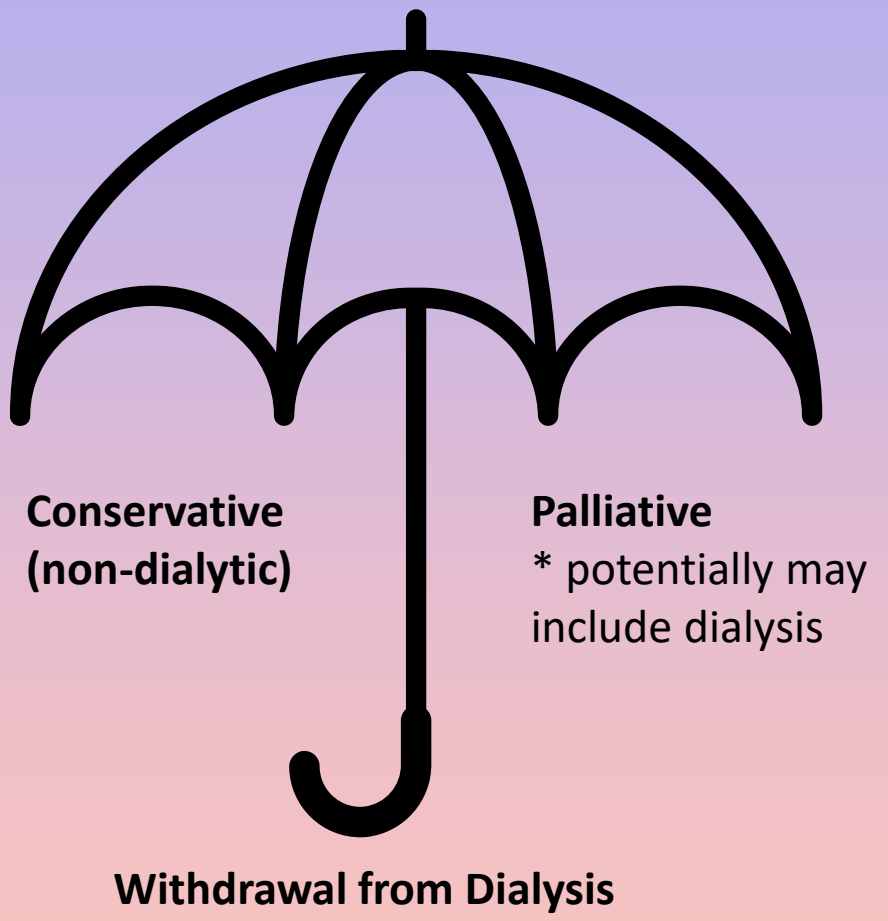

| Age | eGFR | Death /1000 patient yrs. | ESRD / 1000 patient yrs. |
|---|---|---|---|
| 75-84 | 15-29 | 15.4 | 6.31 |
| | <15 | 27.0 | 44.7 |
| >85 | 15-29 | 25.3 | 2.65 |
| | <15 | 49.4 | 29.2 |

**O'Hare et al (2007)**: 209,622 US veterans' database, patients aged ≥ 75 years with Stage 4 and lower CKD had a higher risk of dying from a competing illness

# CONSERVATIVE CARE

- "Active management without dialysis" –
  - **Interventions** with aims to
    - **Delay CKD** progression
    - **Minimize risk** of adverse events & complications
    - Relieve **symptoms**
  - Detailed **communication**, advance care planning
  - **Support**: psychologic, social, family, spiritual
  - **DOES NOT include dialysis**

Davidson et al., 2015 / Murtagh et al., 2016



# Why conservative care?

- 1960s – maintenance dialysis available in the US
- Early legislation / intent of dialysis as a bridge to transplant or renal recovery
- 1978 – 25% incident dialysis patients ≥ 65 y.o., ~10% had DM
- 2016 – 50% incident dialysis patients ≥ 65 y.o., 25% > 75 y.o, 47% had kidney failure from DM

# Why conservative care?

"**Dialysis is widely understood as the default standard of care** for kidney failure that cannot be treated by transplantation. Implicit in this are **2 assumptions** […]

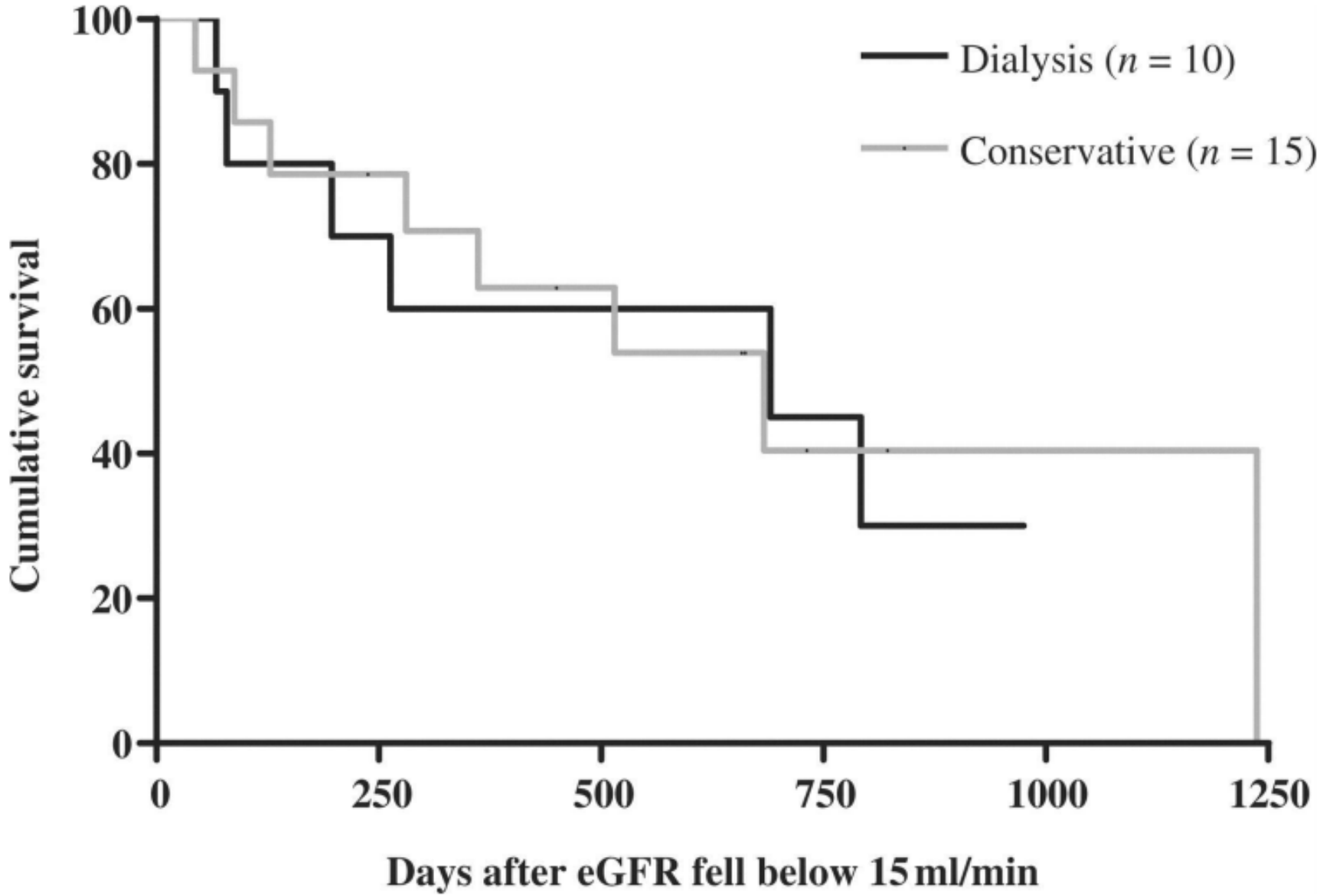
**Everyone benefits from dialysis**

**Alternative to dialysis is imminent death**"

- AJKD Core Curriculum: Kidney Supportive Care 2020

# Everyo

**Kaplan–Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups (log rank statistic <0.001, df 1, P = 0.98).**




Murtagh F E M et al. Nephrol. Dial. Transplant. 2007;22:1955-1962

# 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

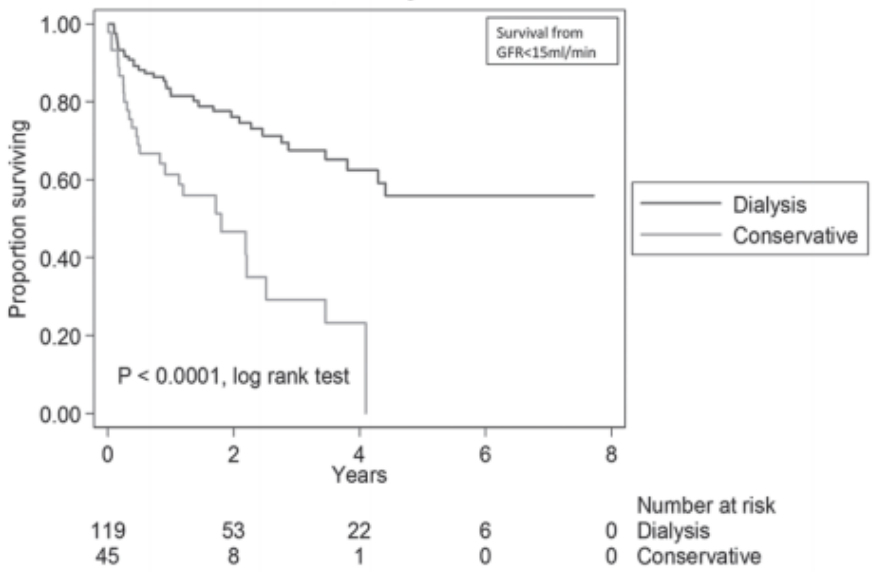
**Jamilla A Hussain** *Leeds Teaching Hospitals NHS Trust, Leeds, UK*
**Andrew Mooney** *Renal Unit Leeds Teaching Hospitals NHS Trust, Leeds, UK*
**Lynne Russon** *Sue Ryder Wheatfields Hospice, Leeds, UK; Leeds Teaching Hospitals NHS Trust, Leeds, UK*

## Retrospective study

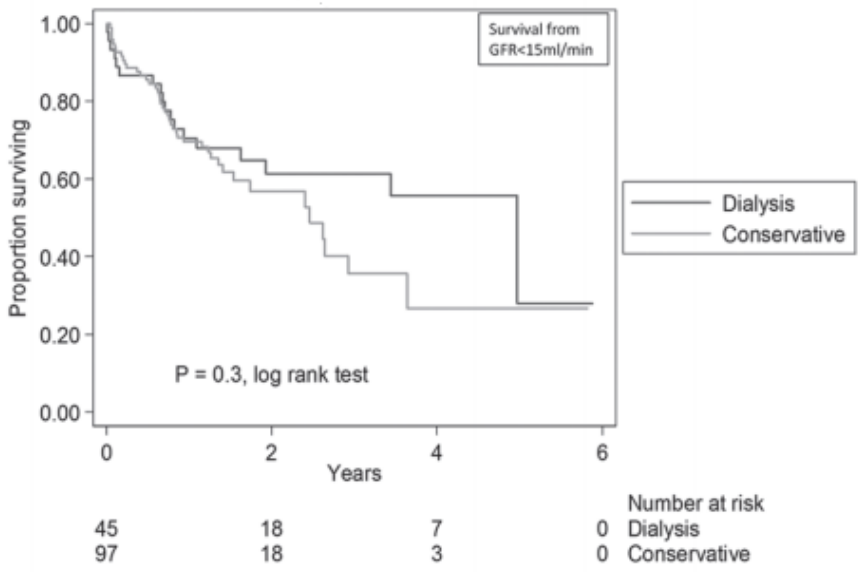
**P:** patients aged > 70 with Stage 5 CKD
**I:** 172 conservative
**C:** 269 RRT
**O:** survival, hospital admissions

**GFR < 15**

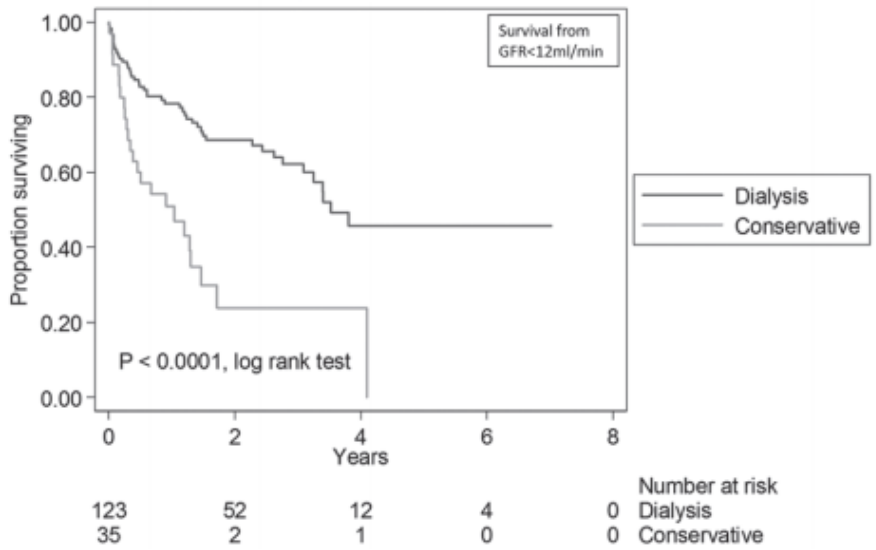
**Age < 80**

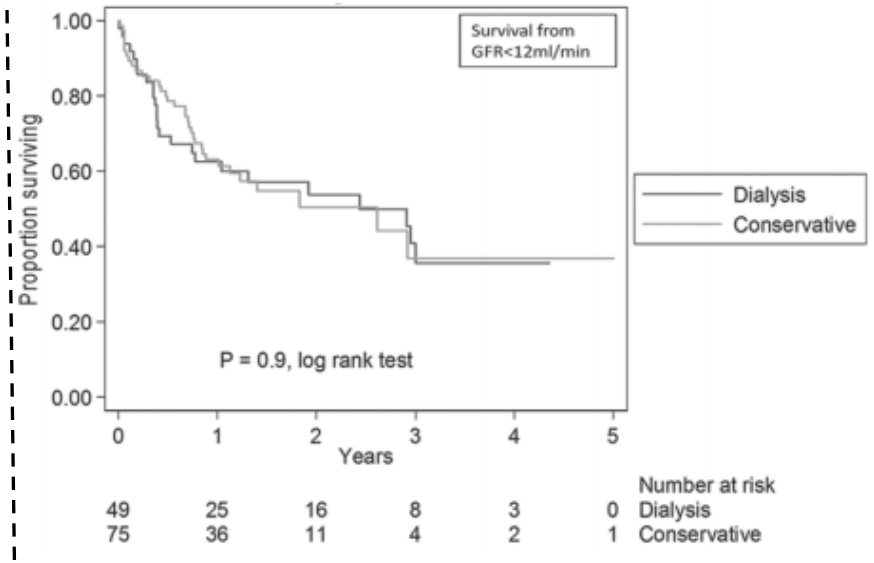



**Age 80+**




**GFR < 12**



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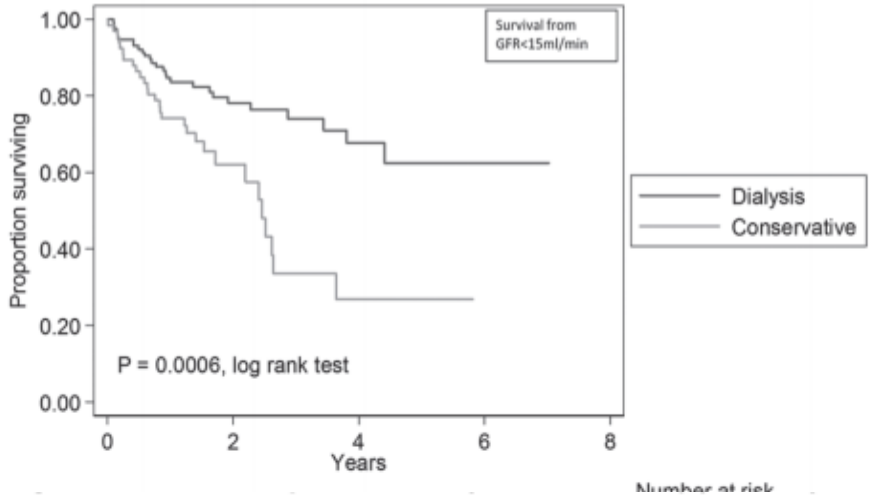
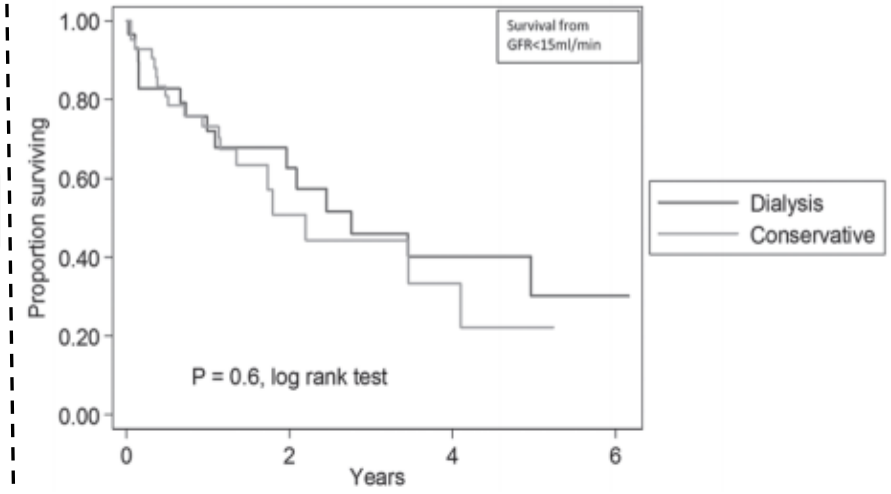
**GFR < 15**

**WHO < 3**




**WHO 3+**




**Results:** In total, 172 patients chose conservative management and 269 chose renal replacement therapy. The renal replacement therapy group survived for longer when survival was taken from the time estimated glomerular filtration rate <20 mL/min ($p < 0.0001$), <15 mL/min ($p < 0.0001$) and <12 mL/min ($p = 0.002$). When factors influencing survival were stratified for both groups independently, renal replacement therapy failed to show a survival advantage over conservative management, in patients older than 80 years or with a World Health Organization performance score of 3 or more. There was also a significant reduction in the effect of renal replacement therapy on survival in patients with high Charlson's Comorbidity Index scores. The relative risk of an acute hospital admission (renal replacement therapy vs conservative management) was 1.6 ($p < 0.05$; 95% confidence interval = 1.14–2.13). A total of 47% of conservative management patients died in hospital, compared to 69% undergoing renal replacement therapy (Renal Registry data). Seventy-six percent of the conservative management group accessed community palliative care services compared to 0% of renal replacement therapy patients.

**Conclusions:** For patients aged over 80 years, with a poor performance status or high co-morbidity scores, the survival advantage of renal replacement therapy over conservative management was lost at all levels of disease severity. Those accessing a conservative management pathway had greater access to palliative care services and were less likely to be admitted to or die in hospital.

Years

| | | | Number at risk | |
|---|---|---|---|---|
| 123 | 49 | 7 | 0 | Dialysis |
| 49 | 6 | 1 | 0 | Conservative |

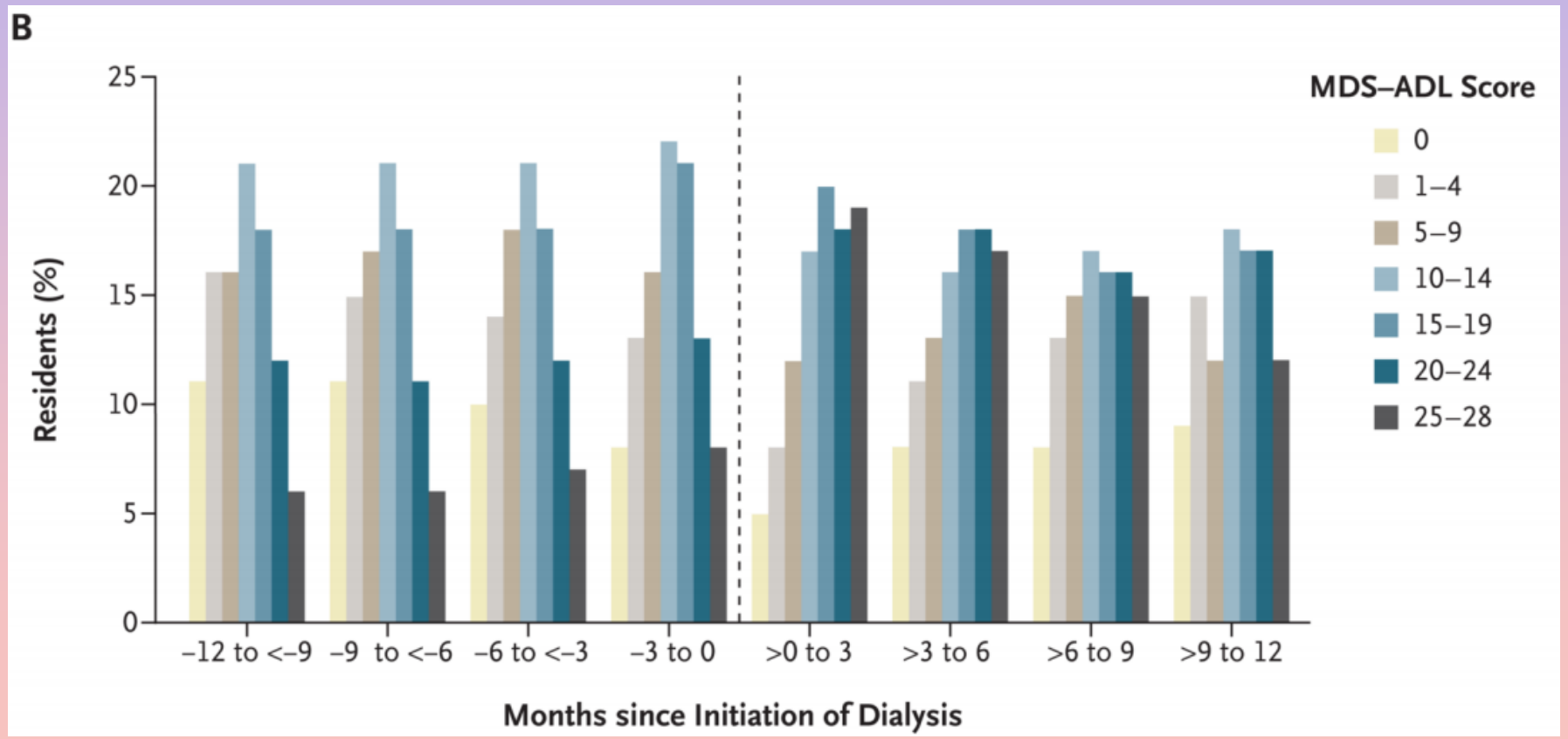
Years

| | | | Number at risk | |
|---|---|---|---|---|
| 31 | 10 | 3 | 1 | Dialysis |
| 35 | 6 | 2 | 0 | Conservative |

# Dialysis in the NH Population

## Functional Status of Elderly Adults before and after Initiation of Dialysis

Manjula Kurella Tamura, M.D., M.P.H., Kenneth E. Covinsky, M.D., M.P.H., Glenn M. Chertow, M.D., M.P.H., Kristine Yaffe, M.D., C. Seth Landefeld, M.D., and Charles E. McCulloch, Ph.D.




3702 NH residents in US over 2-year period.

# Alternative to dialysis is not imminent death

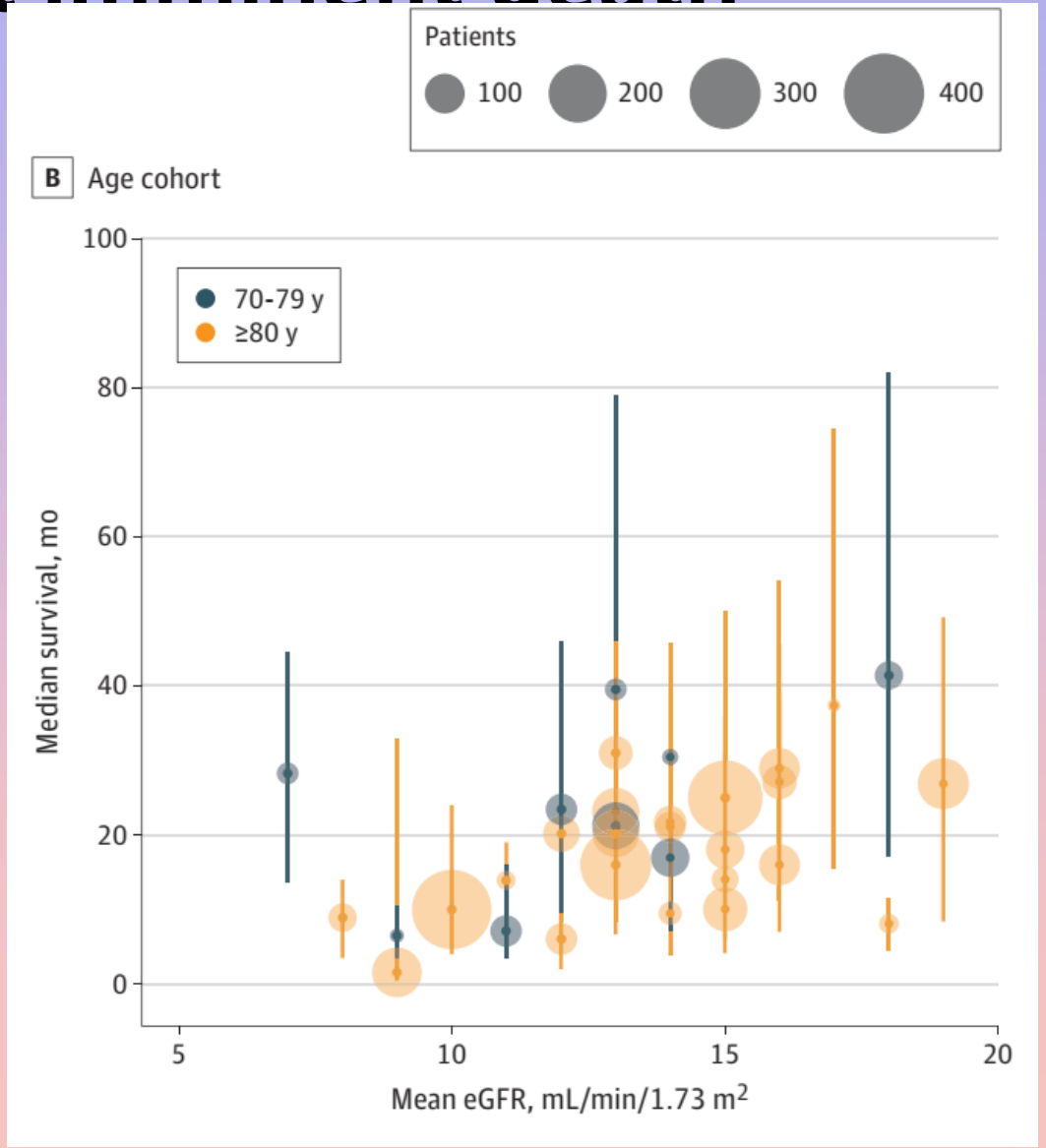
Original Investigation | Nephrology

**Long-term Outcomes Among Patients With Advanced Kidney Disease Who Forgo Maintenance Dialysis**

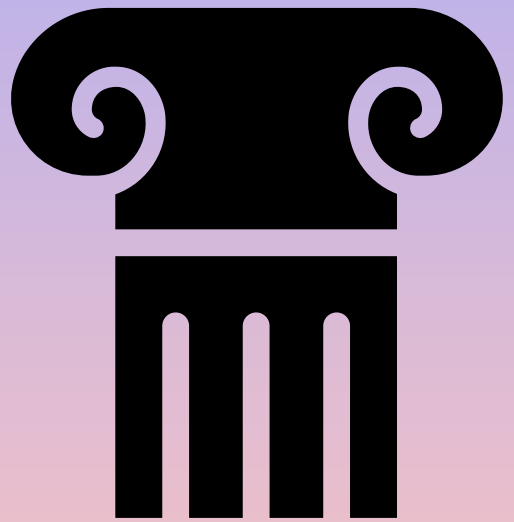
A Systematic Review

Susan P. Y. Wong, MD, MS; Tamara Rubenzik, MD; Leila Zelnick, PhD; Sara N. Davison, MD; Diana Louden, MLib; Taryn Oestreich, MPH, MCHES; Ann L. Jennerich, MD, MS

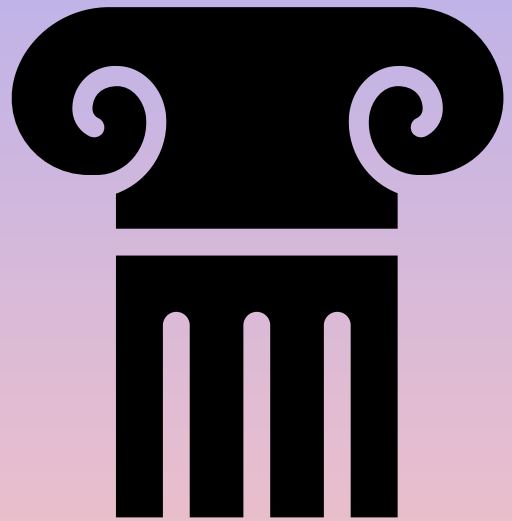
- Systematic review of observational studies (3754 patients) showed a wide range of **median survival from 1 – 41 months**



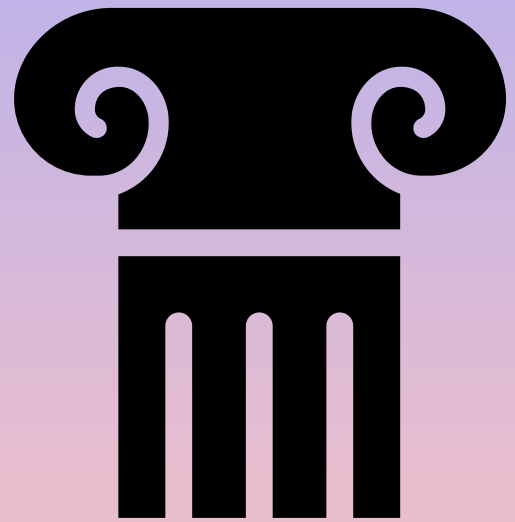
# PILLARS OF CONSERVATIVE CARE



**CLINICAL MANAGEMENT**
- Symptom management
- CKD Management



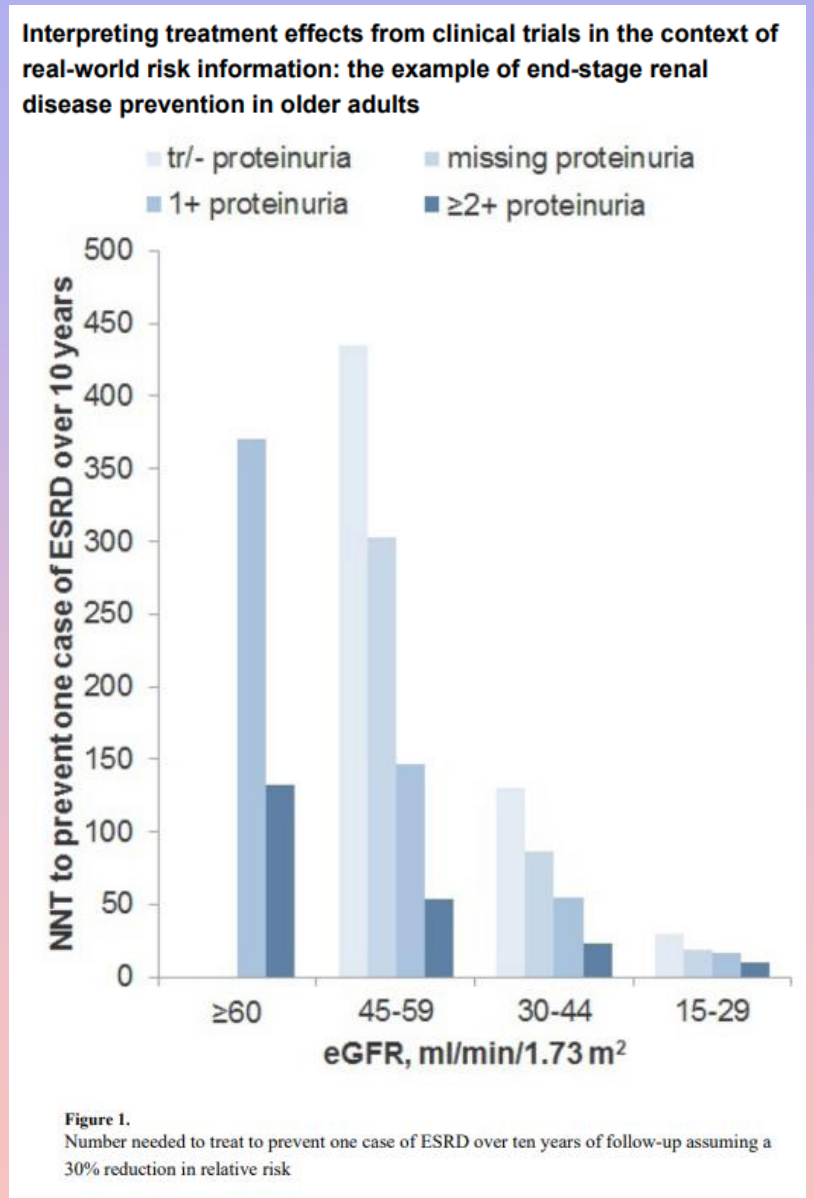
**GOALS OF CARE DISCUSSION**
- Relationship building
- Advanced care directives



**PATIENT & FAMILY SUPPORT**
- Establish supportive resources
- Assisting with grief & loss

# CKD Progression in Context

- Examples of high yield strategies to slow CKD progression:
  - BP control
  - RAAS inhibition / SLGT2 inhibitor
  - A1c control
- All come with potential downsides (side effects, pill burden)
- Does the effect & strength of evidence justify the use in your specific patient?



# Conservative care and CKD complications

| Complication | Significance? | Rationale / Comments |
|---|---|---|
| Anemia | Yes, to an extent | **Target Hgb** 95 – 120 g/L (?110 g/L)<br>**Iron saturation > 20%:** oral or IV iron<br>**EPO** (less concern of relative contraindications. E.g., cancer, stroke) |
| Electrolytes / acid-base | Yes, to an extent | K 6.5 mM = + arrythmia risk<br>Consider discontinuing ACE/ARB/MRA; Dietary review; Bowel routine; K-binders with caution<br>Metabolic acidosis (Low bicarb): aim $HCO_3$ > 20 if possible – diet, NaHCO3 tabs |
| BMD | Not really | In general, limited evidence of normalizing values (esp. PTH)<br>PO4 may contribute to RLS and pruritus: binders if helpful<br>Potential harm with malnutrition |
| BP / volume | BP – yes to an extent<br>---<br>Volume – ++ important | Individualized approach<br>AHA: sBP < 150 mmHg (HYVET)<br>---<br>Volume in relation to comfort / avoidance of pulmonary edema: diuretics |
| Uremic symptoms | Very important | Symptomatic management with medications |

# Symptom management

- Patients under-report symptoms unless asked explicitly
- Various symptom assessment tools
  - E.g., ESAS-r: RENAL (0 to 10 scale)
- Can be related to complications of *fluid overload* or *uremia*

| Symptom | Prevalence in Patients on HD in the United States | Prevalence in Patients on Comprehensive Conservative Care in the United Kingdom |
|---|---|---|
| Fatigue/ weakness | 68% | 75% |
| Dry skin | 72% | 35% |
| Pruritus | 54% | 56% |
| Pain (bone or joint) | 50% | 56% |
| Dry mouth | 45% | 20% |
| Insomnia | 44% | 36% |
| Muscle cramps | 43% | NR |
| Diarrhea | 17% | 11% |
| Worrying/anxiety | 28% | 42% |
| Shortness of breath | 19% | 49% |
| Decreased appetite | 29% | 58% |
| Feeling sad or depressed | 24% | 33% |
| Restless legs | 29% | 24% |
| Nausea | 26% | 36% |
| Constipation | 21% | 42% |
| Vomiting | 11% | 25% |

# Breathlessness

- Volume assessment (and consider differential causes… including metabolic acidosis)
- Increasing dose of Lasix (remember lower GFRs require higher dose of Lasix) - - - up to 120 mg bid
- Consider addition of Metolazone 2.5 mg – 5 mg daily
- Non-pharmacologic management:
  - Sitting in upright position
  - Fan blowing in the room; maintaining humidity
  - Meditation, mindfulness
  - Supplemental O2
- Consider opioids
  - Episodic – fentanyl 12.5 mcg subcut. q1h PRN (fast-acting)
  - More constant – hydromorphone 0.5-1 mg q4h ATC and q1h prn

# Edema

- Volume review. Consider alternative causes – lymphedema, venous stasis, liver/heart failure, thrombosis, poor mobility, amlodipine
- Non-pharmacologic: elevate legs, compression, encourage movement, Na restriction <2 g
- Increasing dose of Lasix (remember lower GFRs require higher dose of Lasix) - - - up to 120 mg bid
- Consider addition of Metolazone 2.5 mg – 5 mg daily

# What happens if the Cr goes up?

**What are we trying to achieve?**

- "Hyper-Creatinemia" – modern concept in heart failure literature
  - Hemoconcentration / higher Cr elevations associated with improved survival (Van der Meer, 2013; Testani et al., 2010)
  - Improvement in renal function for patients with ADHF associated with higher risk of death

**Cr & Ur is a marker of clearance, not injury**

- Withdrawal of diuretics has been associated with true markers of tubular injury (urinary KIM-1, NAG) - Damman et al., 2011 (JACC)

# Uremic pruritus

- Common and should be considered eGFR < 30
- Uremic alterations in the immunochemical milieu of the skin
- Can be experienced in a wide range of ways
- Affects mood, sleep, and social function

| Characteristic | Data |
|---|---|
| Pruritus area* | |
| | 17 (12.8) |
| | 31 (23.3) |
| | 12 (9.0) |
| | 32 (24.1) |
| | 47 (35.3) |
| | |
| | 13 (9.8) |
| | 52 (39.1) |
| | 34 (25.6) |
| | 17 (12.8) |
| | 17 (12.8) |
| | |
| | 4 (3.0) |
| | 67 (50.4) |
| | 49 (36.8) |
| | 13 (9.8) |

| Factor | No effect | Ameliorating | Exacerbating |
|---|---|---|---|
| Rest | 26% | 2% | 57% |
| Dry skin | 46% | 1% | 42% |
| Heat | 57% | 4% | 35% |
| Sweat | 47% | 1% | 33% |
| Clothing (eg, wool) | 73% | 0% | 19% |
| Stress | 71% | 2% | 19% |
| Eating | 78% | 1% | 13% |
| Before dialysis | 73% | 0% | 13% |
| Activity | 23% | 57% | 5% |
| Sleep | 46% | 46% | 0% |
| Hot shower | 33% | 44% | 8% |
| Cold shower | 32% | 39% | 2% |
| Cold | 60% | 28% | 5% |
| Tiredness | 81% | 5% | 5% |
| Physical effort | 74% | 4% | 6% |
| During dialysis | 62% | 11% | 19% |
| After dialysis | 53% | 14% | 19% |

# Uremi

- Contributir
  - Xerosis
  - Drug hy
  - PO4 / C
- Non-pharm
  - Baths >
  - Cool an
  - Maintai
- Localized re
  - **Mentho**
  - Capsaic
- Generalized
  - **Gabape**

AJKD
Original Investigation

## Treatment of Uremic Pruritus: A Systematic Review

*Elizabeth Simonsen, BSc,[1] Paul Komenda, MD, MHA,[1,2,3,4] Blake Lerner, BSc,[1] Nicole Askin, MLIS,[5] Clara Bohm, MD,[1,2,3] James Shaw, MD,[1,2] Navdeep Tangri, MD, PhD,[1,2,3,4] and Claudio Rigatto, MD, MSc[1,2,3,4]*

**Background:** Uremic pruritus is a common and burdensome symptom afflicting patients with advanced chronic kidney disease (CKD) and has been declared a priority for CKD research by patients. The optimal treatments for uremic pruritus are not well defined.

**Study Design:** Systematic review.

**Setting & Population:** Adult patients with advanced CKD (stage ≥ 3) or receiving any form of dialysis.

**Selection Criteria for Studies:** PubMed, CINAHL, Embase, International Pharmaceutical Abstracts, Scopus, Cochrane Library, and ClinicalTrials.gov from their inception to March 6, 2017, were systematically searched for randomized controlled trials (RCTs) of uremic pruritus treatments in patients with advanced CKD (stage ≥ 3) or receiving any form of dialysis. 2 reviewers extracted data independently. Risk of bias was assessed using the Cochrane Collaboration risk-of-bias tool.

**Intervention:** Any intervention for the treatment of uremic pruritus was included.

**Outcomes:** A quantitative change in pruritus intensity on a visual analogue, verbal rating, or numerical rating scale.

**Results:** 44 RCTs examining 39 different treatments were included in the review. These treatments included gabapentin, pregabalin, mast cell stabilizers, phototherapy, hemodialysis modifications, and multiple other systemic and topical treatments. The largest body of evidence was found for the effectiveness of gabapentin. Due to the limited number of trials for the other treatments included, we are unable to comment on their efficacy. Risk of bias in most studies was high.

**Limitations:** Heterogeneity in design, treatments, and outcome measures rendered comparisons difficult and precluded meta-analysis.

**Conclusions:** Despite the acknowledged importance of uremic pruritus to patients, with the exception of gabapentin, the current evidence for treatments is weak. Large, simple, rigorous, multiarm RCTs of promising therapies are urgently needed.

*Am J Kidney Dis.* 70(5):638-655. 

# Restless legs

- Affects approximately 25% of non-HD CKD patients
- Irresistible urge to move, relieved by movement, worsen before to bed
- Associated with poor sleep quality, low QOL, higher risk of CV disease
- Unclear mechanism (?dopaminergic system)

# Restless legs

- Correct iron deficiency
- Remove drugs that can be may be contributing
  - Dopamine antagonists – antipsychotic (Haldol, Risperidone, Quetiapine, Olanzapine); metoclopramide
  - Antidepressants – various including Mirtazapine, SSRIs (citalopram, fluoxetine, sertraline); SNRIs (duloxetine, venlafaxine)
- Avoid alcohol, caffeine, nicotine
- Stretching, exercise
- Pharmacologic therapies
  - Dopamine agonists: Pramipexole 0.125 mg 2 hrs before bed or Ropinirole 0.25 mg 2 hrs before bed
  - Gabapentin or Lyrica

# GOALS OF CARE DISCUSSIONS

## Family Members' Understanding of the End-of-Life Wishes of People Undergoing Maintenance Dialysis

*Fahad Saeed,[1] Catherine R. Butler,[2,3] Carlyn Clark,[4] Kristen O'Loughlin,[5] Ruth A. Engelberg,[6,7] Paul L. Hebert,[3,8] Danielle C. Lavallee,[8,9] Elizabeth K. Vig,[3,10] Manjula Kurella Tamura,[11,12] J. Randall Curtis,[6,7] and Ann M. O'Hare[2,3]*

**Abstract**

**Background and objectives** People receiving maintenance dialysis must often rely on family members and other close persons to make critical treatment decisions toward the end of life. Contemporary data on family members' understanding of the end-of-life wishes of members of this population are lacking.

**Design, setting, participants, & measurements** Among 172 family members of people undergoing maintenance dialysis, we ascertained their level of involvement in the patient's care and prior discussions about care preferences. We also compared patient and family member responses to questions about end-of-life care using percentage agreement and the $\kappa$-statistic.

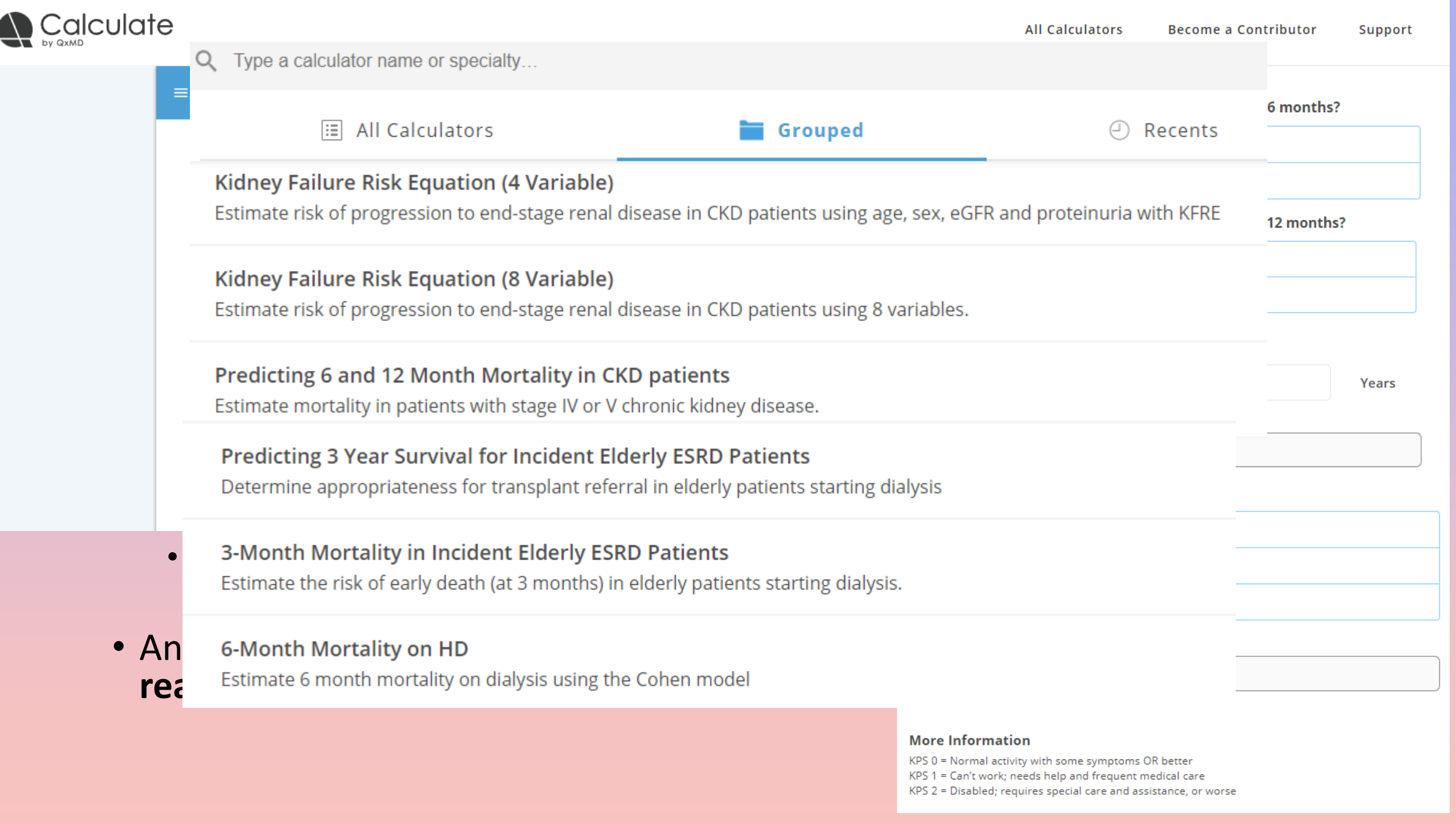
**Results** The mean (SD) age of the 172 enrolled family members was 55 (±17) years, 136 (79%) were women, and 43 (25%) were Black individuals. Sixty-seven (39%) family members were spouses or partners of enrolled patients. A total of 137 (80%) family members had spoken with the patient about whom they would want to make medical decisions, 108 (63%) had spoken with the patient about their treatment preferences, 47 (27%) had spoken with the patient about stopping dialysis, and 56 (33%) had spoken with the patient about hospice. Agreement between patient and family member responses was highest for the question about whether the patient would want cardiopulmonary resuscitation (percentage agreement 83%, $\kappa$=0.31), and was substantially lower for questions about a range of other aspects of end-of-life care, including preference for mechanical ventilation (62%, 0.21), values around life prolongation versus comfort (45%, 0.13), preferred place of death (58%, 0.07), preferred decisional role (54%, 0.15), and prognostic expectations (38%, 0.15).

**Conclusions** Most surveyed family members reported they had spoken with the patient about their end-of-life preferences but not about stopping dialysis or hospice. Although family members had a fair understanding of patients' cardiopulmonary resuscitation preferences, most lacked a detailed understanding of their perspectives on other aspects of end-of-life care.

*CJASN* 16: 1630–1638, 2021. doi: https://doi.org/10.2215/CJN.04860421

# GOALS OF CARE DISCUSSIONS

- **Illness understanding**
  - Renal trajectory but also in context of other comorbidities / functional status
- **Elicit values and define goals**
  - Explore patient's past experiences, hopes, values, priorities
  - Patient's perception of quality of life
  - Ask patients to describe goals for future care
- **Questions**: allow questions and resolve concerns
- **Advance care planning** – SDM, Code Status
- **Reviewing (and re-reviewing)** current management plan in context of GOC


Calculate
by QxMD
All Calculators
Become a Contributor
Support
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All Calculators
Grouped
Recents
Kidney Failure Risk Equation (4 Variable)
Estimate risk of progression to end-stage renal disease in CKD patients using age, sex, eGFR and proteinuria with KFRE
Kidney Failure Risk Equation (8 Variable)
Estimate risk of progression to end-stage renal disease in CKD patients using 8 variables.
Predicting 6 and 12 Month Mortality in CKD patients
Estimate mortality in patients with stage IV or V chronic kidney disease.
Predicting 3 Year Survival for Incident Elderly ESRD Patients
Determine appropriateness for transplant referral in elderly patients starting dialysis
3-Month Mortality in Incident Elderly ESRD Patients
Estimate the risk of early death (at 3 months) in elderly patients starting dialysis.
6-Month Mortality on HD
Estimate 6 month mortality on dialysis using the Cohen model
6 months?
12 months?
Years
More Information
KPS 0 = Normal activity with some symptoms OR better
KPS 1 = Can't work; needs help and frequent medical care
KPS 2 = Disabled; requires special care and assistance, or worse

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# GOALS OF CARE DISCUSSIONS

- **Open ended questions are useful**
  - “What do you understand about your current illness”
  - “What are you hoping to achieve out of the care you receive”?

- **Reframing** – no dialysis is not a subtractive decision; it may **add tremendous value** to patient care
  - “Care vs. cure”
  - Survival-focused vs. Comprehensive / Holistic care

- Answering the question of **what a renal death looks like** (it’s peaceful) and **reassurance of ongoing support**

# PATIENT AND FAMILY SUPPORT

- **Home visits** (NP at our site)
- **Networking** with Palliative Care Team
- **Crisis Action Plan**
  - A clear protocol to follow to avoid unnecessary hospitalizations and rapid response to deal with severe **physical symptoms** & **emotional distress** (pt. and caretakers!)
  - Helps avoid dialysis as a “last minute fix” when things go wrong
- Social work support / Spiritual care to help family cope with patient’s journey

CONSERVATIVE KIDNEY MANAGEMENT

Patient label placed here (if applicable) or if labels are not used, minimum information below is required.

| |
|---|
| Name *(last first)* |
| Birthdate *(yyyy-Mon-dd)* |
| Gender |
| PHN |

# My Crisis Action Plan

**What is a crisis action plan?**

A crisis action plan is used to plan for and be prepared for a decline in your kidney function. This plan will help you: know who to call (SUPPORT), which medication to take (SYMPTOM) and what to do in an EMERGENCY, as your kidney function worsens.

| SUPPORT | SYMPTOMS | EMERGENCY |
|---|---|---|

## SUPPORT:

My Family Physician: _____ Phone Number: _____

Fax Number: _____ (required when you do not have a Home Care Case Manager)

My Home Care Case Manager: _____ Phone Number: _____

My Chronic Kidney Disease Clinic: _____ Phone Number: _____

My Pharmacy: _____ Phone Number: _____

If you are living at home and require daily assistance (with showering/dressing/toileting/medication), we strongly encourage you to have **homecare** involved**.** The home care relationship will be *very* important if you start to have trouble at home and need care quickly. This could include helping you go somewhere else to live, such as a long-term care facility or hospice, if you can no longer manage at home. You can refer yourself or your loved one to homecare – you can learn more at **www.ckmcare.com** under "Resources".

It is also important that you have engaged in **advance care planning**, and that you have a personal directive and a signed Goals of Care designation form in your **Green Sleeve** at home. For further information, please speak to a clinic nurse.

## SYMPTOMS:

**What can I expect?**

When your kidney function gets very poor, there are some common symptoms that you might experience. These could include **nausea/vomiting, itchiness, sleep difficulties, restless legs, and trouble breathing**. You might have **pain** from other conditions as well. Your care provider can give you more information on each of these symptoms and can help you manage them.
You might start to experience other symptoms that we are not able to reverse. These include loss of appetite, muscle twitching, drowsiness, tiredness, and confusion. Some of these symptoms may be more distressing than others.

**How can I be prepared?**

In addition to caring for your symptoms using things such as: heat packs, music therapy, relaxation techniques etc., you can take **prescribed medication** to help you relieve your distressing symptoms. You and your health care provider should discuss which kind, how much and how often you should take your medication, to address each symptom.

CONSERVATIVE KIDNEY MANAGEMENT

# My Crisis Action Plan

Use this table to organize your medications for when you are experiencing:

| |
|---|
| **Pain Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Shortness of Breath Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Nausea/Vomiting Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Restlessness/Confusion Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Any Other Symptom(s)** (Ie. Hyperkalemia) _____ **Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |

- Keep a record of what you take, when you took it, and what your response to the medicine was.
- See or talk to one of your health care providers (as noted under **SUPPORT**) on a **regular basis**.

## EMERGENCY:

If a symptom is getting worse quickly or is very bad, **call your family physician, home care case manager or Chronic Kidney Disease Clinic**. Try to call your family physician or home care case manager first. They might be able to give you guidance about your medicine and how to address your emergency..

If needed, the above people can access **Emergency Medical Service Palliative & End of Life Care Assess, Treat and Refer on your behalf**. While working collaboratively with your care team, EMS professionals will attempt to treat your palliative symptoms (such as shortness of breath or pain) in your home.

Depending on the situation, EMS personnel may need to transport you to the hospital for further testing or treatment. Make sure to take your green sleeve with you to the hospital.

**If you are unable to reach your family physician, home care case manager or Chronic Kidney Disease Clinic, and your symptoms are severe, phone 911.**

- Tell the EMS personnel **in your home** that:
  - You have end stage kidney disease
  - You have **CHOSEN Conservative Kidney Management –** you have chosen **not to have dialysis** of any kind.
  - You are receiving **palliative care.**
- Have your green sleeve ready to give to EMS, including your **crisis action plan** and the **Health Care Professional (HCP) Crisis Action Plan**.

# HOW CAN WE WORK BETTER TOGETHER?

- **Clear communication** & **well-defined roles** between PCP / Nephrologist / Other Consultants
- **Systematic documentation** to track symptom burden
- **Patient Care Plans**

# Letter to Primary Care Provider

Dear Colleague,

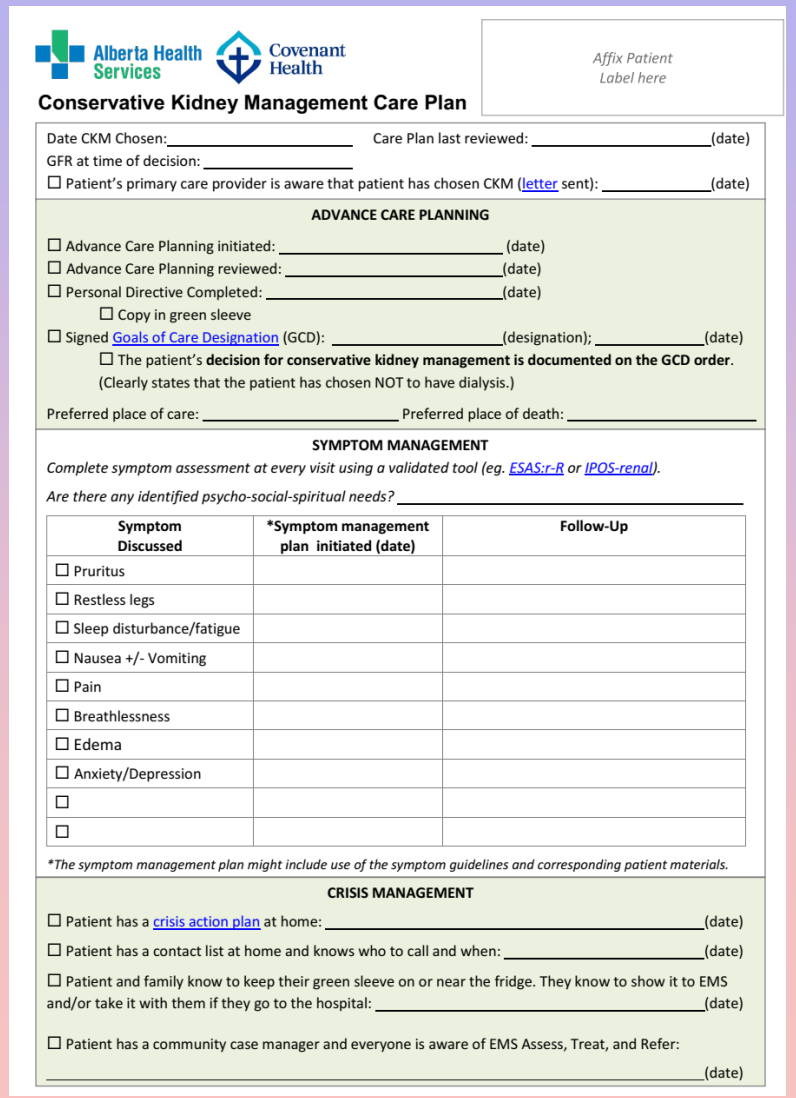
Our mutual patient (_____) has advanced chronic kidney disease and is being followed by the Chronic Kidney Disease (CKD) Clinic for this condition. The patient has been fully informed of his or her treatment options, and it has been agreed upon by the patient, family, and kidney healthcare team that will pursue a conservative kidney management strategy. This means that the patient has chosen not to have dialysis of any kind. This decision for conservative kidney management was based on the patient's values, preferences, overall health, general function, and individual situation.

The progression of kidney disease is highly variable and it may be that the patient's kidney function remains stable for some time. For as long as the patient is interested in attending the CKD Clinic, we will continue to manage _____'s kidney disease in the clinic with a focus on quality of life. This includes interventions aimed at preserving the patient's remaining kidney function, avoiding complications related to end stage kidney disease, and managing the patient's symptoms. We will also continue to review the patient's wishes and we will regularly communicate our assessment findings with you.

As the patient's kidney function declines to very low levels and symptoms of uremia develop, end of life care will need to be coordinated and the patient may no longer wish to or be able to attend the CKD Clinic. At that time or at any other time, it may be determined jointly between you, the patient, and the kidney healthcare team that the patient's kidney disease needs may be best met by you, their primary care provider, in conjunction with support from the community (such as homecare or palliative care). We would not wish to interfere with your management of the patient but would hope to work collaboratively to support the patient's needs and wishes.

To that end, we have developed an interactive online Conservative Kidney Management Clinical Pathway that can be accessed by any care provider. It includes symptom management guidelines, suggestions for chronic kidney disease and crisis management, information on referrals and community resources, and education materials for patients.

# A Patient-centred Care Plan



Alberta Health Services | Covenant Health

**Conservative Kidney Management Care Plan**

*Affix Patient Label here*

Date CKM Chosen:_____ Care Plan last reviewed: _____(date)
GFR at time of decision: _____
☐ Patient's primary care provider is aware that patient has chosen CKM (letter sent): _____(date)

**ADVANCE CARE PLANNING**

☐ Advance Care Planning initiated: _____ (date)
☐ Advance Care Planning reviewed: _____(date)
☐ Personal Directive Completed: _____(date)
☐ Copy in green sleeve
☐ Signed Goals of Care Designation (GCD): _____(designation); _____(date)
☐ The patient's **decision for conservative kidney management is documented on the GCD order**. (Clearly states that the patient has chosen NOT to have dialysis.)

Preferred place of care: _____ Preferred place of death: _____

**SYMPTOM MANAGEMENT**

*Complete symptom assessment at every visit using a validated tool (eg. ESAS:r-R or IPOS-renal).*

*Are there any identified psycho-social-spiritual needs?* _____

| Symptom Discussed | *Symptom management plan initiated (date) | Follow-Up |
|---|---|---|
| ☐ Pruritus | | |
| ☐ Restless legs | | |
| ☐ Sleep disturbance/fatigue | | |
| ☐ Nausea +/- Vomiting | | |
| ☐ Pain | | |
| ☐ Breathlessness | | |
| ☐ Edema | | |
| ☐ Anxiety/Depression | | |
| ☐ | | |
| ☐ | | |

**The symptom management plan might include use of the symptom guidelines and corresponding patient materials.*

**CRISIS MANAGEMENT**

☐ Patient has a crisis action plan at home: _____(date)
☐ Patient has a contact list at home and knows who to call and when: _____(date)
☐ Patient and family know to keep their green sleeve on or near the fridge. They know to show it to EMS and/or take it with them if they go to the hospital: _____(date)
☐ Patient has a community case manager and everyone is aware of EMS Assess, Treat, and Refer: _____(date)

**CKD MANAGEMENT**

Are current medications and investigations in line with the patient's identified goals and disease trajectory?

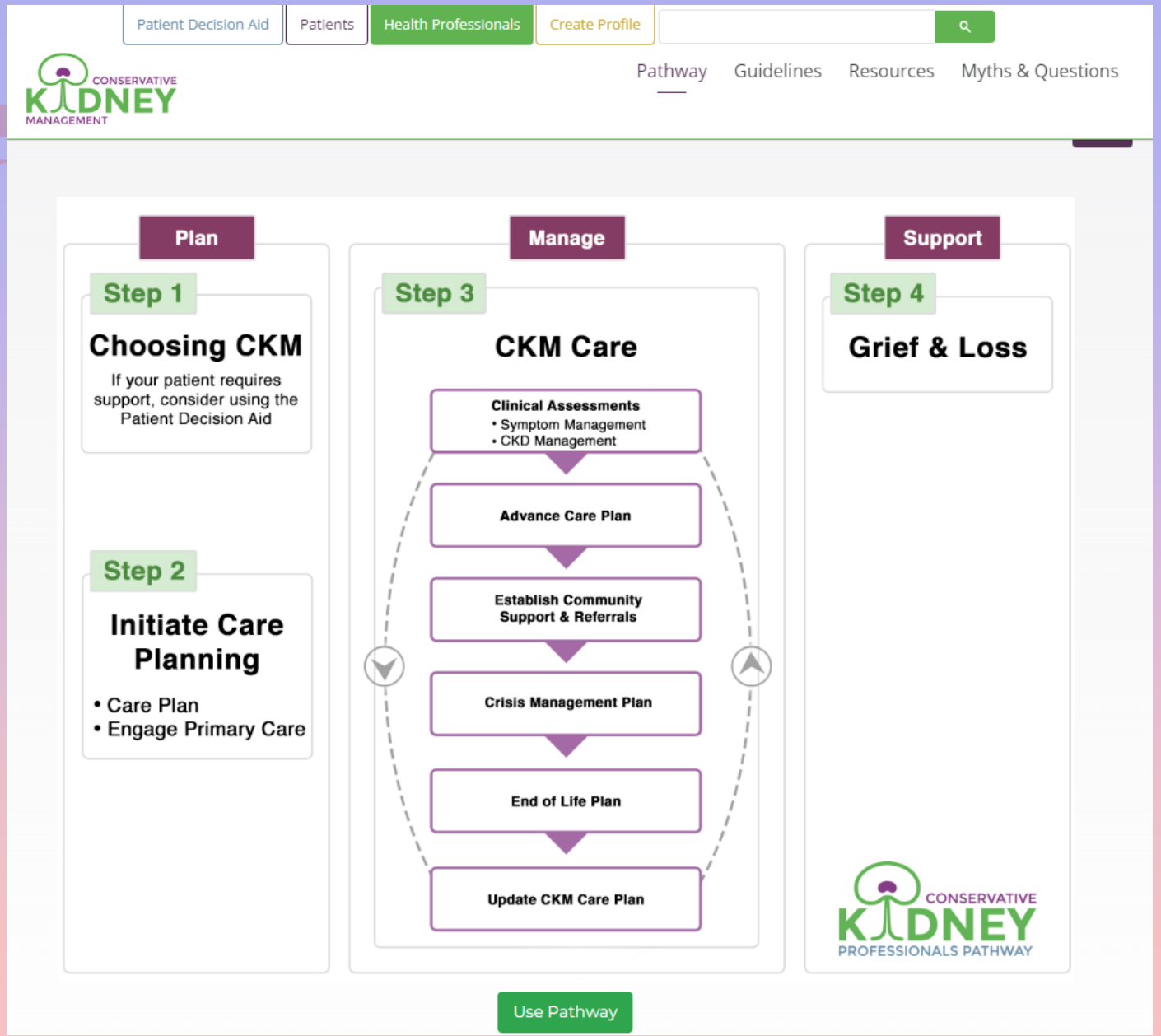
| | |
|---|---|
| Hypertension | Target <160/90 or_____ |
| Dyslipidemia | ☐ Statin discontinued_____ (date)<br>☐ Patient will continue to take statin. Rationale: _____ |
| Hyperkalemia | *Patient and family are aware of implications of treating/not treating high potassium levels:* _____<br>☐ Implement CKM Hyperkalemia Guideline _____(date)<br>☐ Patient has prescription on hand for Kayexalate if appropriate<br>☐ Patient does not wish to monitor potassium _____(date) |
| Hyperphosphatemia | *Assess if patient has symptoms related to high phosphorus.*<br>☐ Implement CKM Hyperphosphatemia Guideline _____(date)<br>☐ Patient does not wish to monitor calcium/phosphorus _____(date) |
| Acidosis | *Explain possible benefits/burdens of treating acidosis.*<br>☐ Implement CKM Acidosis Guideline _____(date)<br>☐ Patient does not wish to monitor for acidosis_____ (date) |
| Anemia | *Patient is aware that treatment of anemia is for purposes of symptom management and will be stopped if no further benefit:* _____<br>☐ Implement CKM Anemia Guideline _____(date)<br>☐ Patient does not wish to monitor for anemia _____(date) |

**COMMUNICATION AND REFERRALS**

☐ Patient is aware of availability of homecare (homecare information given): _____(date)
***When appropriate:***
☐ Social work/spiritual care referrals have been made? SW:_____ (date) / SC:_____ (date)
☐ With patient's permission, referral has been made to homecare (via CCA): _____(date)
☐ Patient assigned to a Palliative Home Care team _____(date) / Contact: _____
☐ Community case manager: _____(name and contact #)
☐ (If in LTC, care manager: _____(name and contact #)
☐ Last contact with home care case manager:_____ (date)
*(Recommend telephone contact every 3 months or as needed)*
☐ Contacted GP to request palliative consult via CCA _____(date)
Reason(s):
☐ Contacted GP to request specialized geriatrics consult _____(date)
Reason(s):

**END OF LIFE and BEREAVEMENT**

☐ With patient's permission, confirm that Alberta Palliative Blue Cross form has been submitted (life expectancy approximately 3 months) – check with GP and/or homecare team.
☐ If patient wishes to die at home or in hospice, patient's goals of care designation is C1 or C2.
☐ Location of care 1 month before death_____
☐ Date and location of death _____ /_____
☐ After patient's death, condolence card sent and/or supportive telephone call made (if appropriate).
☐ If appropriate, bereavement package provided to family.




[Conservative Kidney Management (ckmcare.com)]

# Case #1

- 50M resides from LTC on a dementia unit
- From Vietnam and English is not his first language
- No family members here in Canada
- Patient does verbalize but limited secondary to ischemic stroke
- Dependent for ADLs and IADLs
- Constant observation due to history of aggression
- Currently voids via foley catheter

- Limited role of dialysis
  - ?how much life to gain
  - Delirium / agitation on treatment
  - Access concerns: pulling out HD line
  - Diminished QoL

# CKD Management Case #1

- Home visits done to assess patient's uremic symptoms and treat as needed
- We followed the patient q3months assessing his recent lab results and adjusted patient's medication accordingly
- Hgb 89, Increased dose of Aranesp
- Collaborated with the LTC healthcare team to ensure palliative measures are in place

# CASE #2

- 96F from RH with assisted living
- Independent before transitioning into her new home
- Uses a walker for mobility and able to care for herself
- Recent fall – hip # → assisted living
- Now admitted to hospital for acute pancreatitis / gallstones: treated conservatively, but high likelihood of recurrence

- A focus on goals of care
- Symptom management

# CKD management Case #2

- Goals of care discussions were established during first meeting
- Assisted with family support as patient transitioned from her home to RH
- Assessed patient's edema and weight gain treated with increased Lasix
- K 4.9 patient was on Kayexalate 15 g every other day (long Hx of hyperkalemia)

# CKD Management Case #2 cont’d

- Educated family members and patient on uremic symptoms and developed a crisis management plan (avoid ER visits if possible)
- Reviewed goals of care with patient and family members as patient moved from home to RH
- Collaborated with RH healthcare team to ensure they knew patient’s goals of care and what it meant to be a CKD patient on conservative renal care

# SUMMARY

- Conservative renal care should be explored as an option for many of LTC patients
  - Consider a referral / discussion with nephrology
    - EGFR < 30 – with metabolic (e.g., Hgb < 90, hyperkalemia/acidosis) or volume complications
    - EGFR < 20 – without imminent competing reasons for mortality
  - RRT may be of questionable benefit for LTC patients with ++ comorbidities / advanced age

# SUMMARY

- **Pillars of conservative care**
  - **Medical management:** a focus on symptom management and a sensible approach to target typical CKD risk factors (BP/A1c/reno-protective meds) & CKD complications (anemia/BMD/electrolytes/acid-base)
  - **Goals of care discussions:** Advanced care planning, illness understanding, prognostication, relationship-building
  - **Patient and family support:** a multidisciplinary/collaborative approach; patient-centred care plan & crisis planning

# QUESTIONS?