

THAPS Conference 2017

Renal Supportive Care

Bangkok September 7-8 2017

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St George Hospital Sydney, Australia

How can the principles of Palliative Care
help patients
with Chronic Kidney Disease (CKD)
and End Stage Kidney Disease (ESKD) ?

Scope of Renal Supportive Care

Nephrology and Palliative Care

Nephrology

The care of patients with renal impairment.

1. Diagnosis, monitoring, prevention of deterioration in renal function.

2. Renal Replacement Therapy

Renal Replacement Therapy :

- Haemodialysis
- Peritoneal dialysis
- Renal transplantation

What is Palliative Care ?

WHO definition (2002)

Palliative Care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.



Barriers to effective Palliative Care

Belief that Palliative Care is simply terminal care... “not now, he’s not ready for it”

“It will send the wrong message to her”

“It will just take away her hope.”

Why is Palliative care/ a palliative approach relevant to patients with ESKD ?

1. Epidemiology

Globally

Nation A

May have resources that are universally available and allow elderly, frail, co-morbid patients onto dialysis programs.

Nation B

- Limited resources
- Dialysis reserved for younger, fitter, non-diabetic patients, or

simply reserved for those that can afford dialysis

Nation C

- Poor resources
- Dialysis is not available

DIALYSIS PATIENTS

The characteristics of patients on dialysis have changed over the years.

Essentially more elderly patients with comorbidities.

Age of dialysis patients

In developed nations the mean age of patients commencing RRT is 60 years plus.

In the USA it is 65 years.

In developed nations the age cohort of dialysis patients that has the greatest prevalence is the 65-84 year old group.

In Thailand the age cohort of dialysis patients with the greatest prevalence are the 45 - 64 year old age group.

Thailand Renal Replacement Therapy – Year 2014

Prevalence of dialysis by age groups

45 -64 years 43.5 %

65 years plus 39.4%

Note : 75 years plus -- 17 %

The other aspect of the global change in epidemiology is the rise of Diabetes Mellitus.

The percentage of incident patients with ESKD that have diabetic nephropathy is :

> 50 % in Singapore, Malaysia, New Zealand

40 -50 % in Hong Kong, Taiwan, Republic of Korea, Japan and the USA.

In Thailand the percentage of patients with ESKD who commenced dialysis in 2014 with diabetic nephropathy was 39.6. %

Thailand Renal Replacement Therapy – Year 2014

Does everyone who has ESKD commence dialysis ?

For every patient with ESKD receiving
Renal Replacement Therapy (RRT)

there is another who does not receive
RRT

Australian Institute of Health and Welfare Research,
2011

2. Mortality

ESRD patients

Overall patients with ESKD with or without RRT have a reduced life expectancy compared to age-matched controls.

DIALYSIS

For patients on dialysis 13.3 % die each year (ANZDATA 2016 Report)

For those aged 75 years and older that figure is 25 %

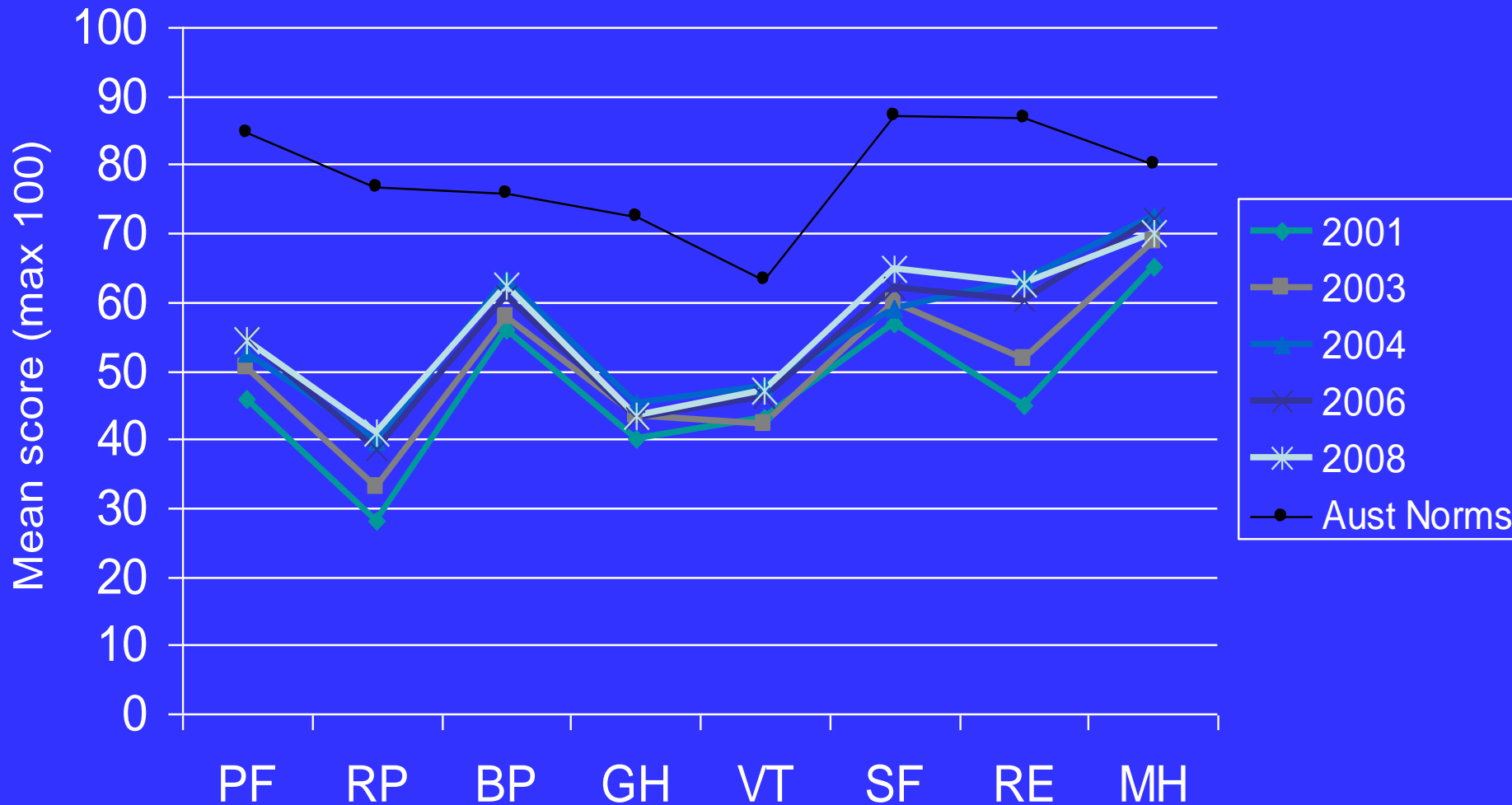
3. Symptomatology

“Patients with CKD, particularly those with ESRD are among the most symptomatic of any chronic disease group.”

Murtagh F, Weisbord S. Symptoms in renal disease. In : Chambers EJ et al (eds) *Supportive Care for the Renal Patient* 2010, 2nd ed, OUP.

4. Quality of life

QOL – dialysis patients (SF-36 Scores) St George Hospital, Sydney



5. The “quality” of dying

The circumstances in which patients with ESRD die varies considerably

If it is an expected death (eg. after the cessation of dialysis) the management of the dying phase is crucial

and the manner of that dying will be remembered forever by the family

Why is Palliative care/ a palliative approach relevant to patients with ESKD ?

1. Epidemiology

2. Mortality

3. Symptomatology

4. Quality of Life

5. Quality of dying

Core competencies in Renal Supportive Care

Realistically, given issues of manpower,
it may not be possible for a Palliative Care
health professional to be present in every
Renal Unit

What are the core competencies for Nephrologists and Renal Nurses in a “Palliative approach” to patients with ESKD?

4 Pillars of a Palliative approach

- Communication
- Symptom management
- Psychosocial support
- Care of the dying patient

What is happening
in Renal Supportive Care?

Internationally

KDIGO Controversies Conference on Supportive Care in CKD.

Mexico City 2013

Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison¹, Adeera Levin², Alvin H. Moss³, Vivekanand Jha^{4,5}, Edwina A. Brown⁶, Frank Brennan⁷, Fliss E.M. Murtagh⁸, Saraladevi Naicker⁹, Michael J. Germain¹⁰, Donal J. O'Donoghue¹¹, Rachael L. Morton^{12,13} and Gregorio T. Obrador¹⁴

Australia and New Zealand

Review

Renal supportive and palliative care: position statement

SU CRAIL, ROB WALKER and MARK BROWN FOR THE RENAL SUPPORTIVE CARE WORKING GROUP*

Reviews

ANZSN Renal Supportive Care Guidelines 2013**THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS**

Mark A Brown¹ and Susan M Crail², ¹Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, and ²Central and North Adelaide Renal and Transplantation Service, Adelaide, South Australia, Australia

2 For dialysis or transplantation.

3 *Indeterminate* – that group for whom the treating nephrologist and the patient are unable to come to a clear decision. For people in this group, seeking a second opinion and ideally, discussing the case at a multidisciplinary team meeting (similar to those discussions surrounding acceptance onto the transplant waiting list) are paths to follow.

A very important principle is that these planning discussions need to take place early in the course of a patient's

Annual National
Renal Supportive Care Symposia

In Sydney, since 2010.

First Australian and New Zealand Renal Supportive Care Master Class

Sydney, 2015

Workshops

on Renal Supportive Care :

- Sri Lanka (2015)
- Ireland (2016)
- Malaysia (2017)
- Khon Kaen, Thailand (September 4 2017)
- Bangkok, Thailand (September 7-8 2017)

USA

*Clinical Practice Guidelines on Shared
Decision-Making in the Appropriate
Initiation of and Withdrawal from Dialysis*

Renal Physicians Association of the USA 2010.

United Kingdom

Annual Symposia on Renal-Palliative Care
co-organised by both disciplines

*National Framework for the
Implementation of End of Life Care in
Advanced Kidney Disease*

2009

Conclusion

Over the past decade there has been an emerging interest, research and engagement at the interface of the two disciplines.

Much work needs to be done at all levels.

Decision making around starting dialysis

Once ESRD is diagnosed it is important to carefully examine the various options

RRT

Conservative

As with any treatment the important thing is for the Nephrologist to carefully weigh up the benefits and burdens of dialysis for this particular patient.

No doctor has an ethical or legal obligation to offer treatment to a patient where they feel that treatment will be excessively burdensome to that patient compared to the benefit.

The first question that is asked –

“Will I live longer if I start dialysis ?”

1. Survival

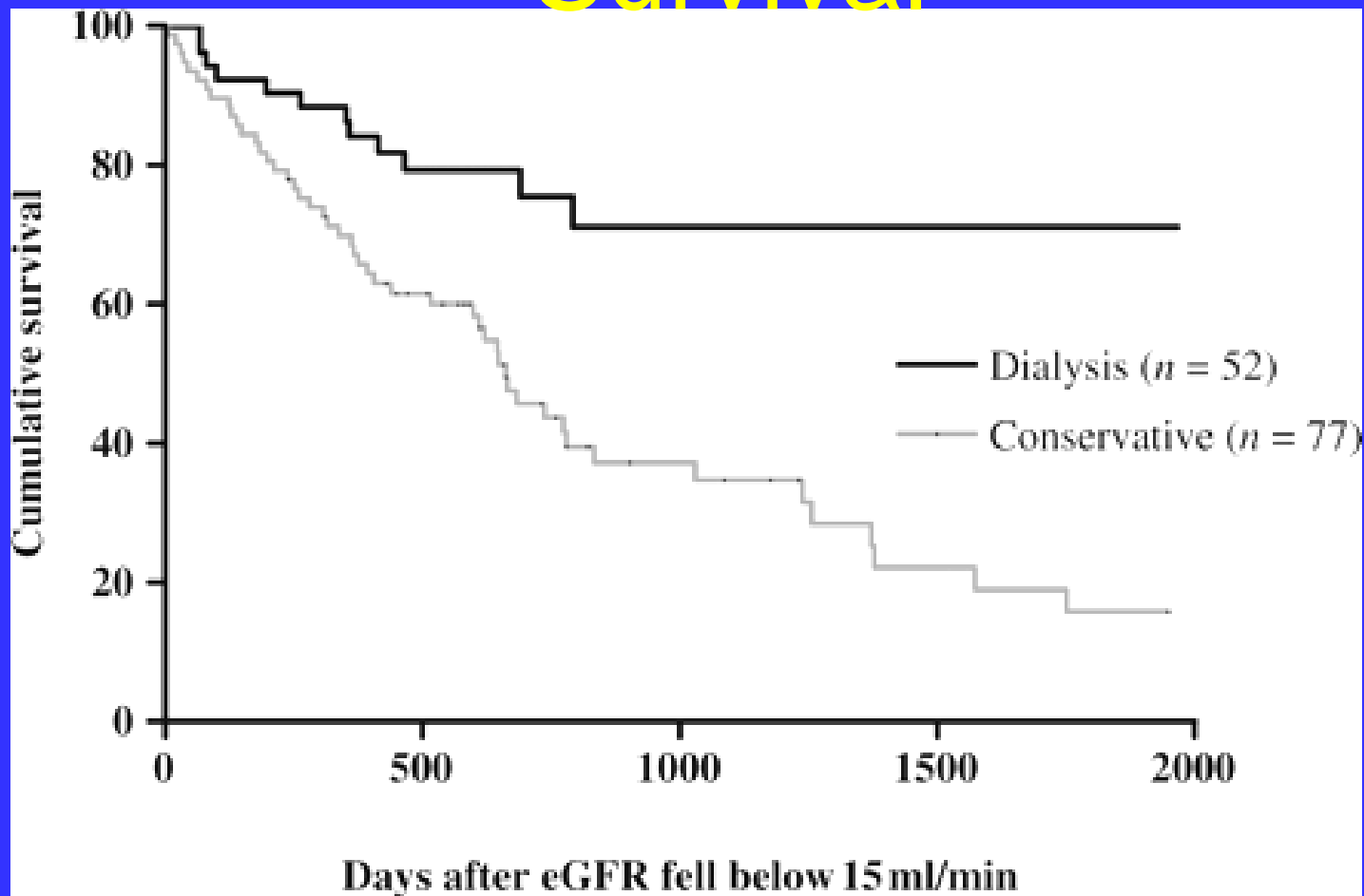
For a long time the assumption was –

Yes, you will always live longer if you commence dialysis than if you do not.

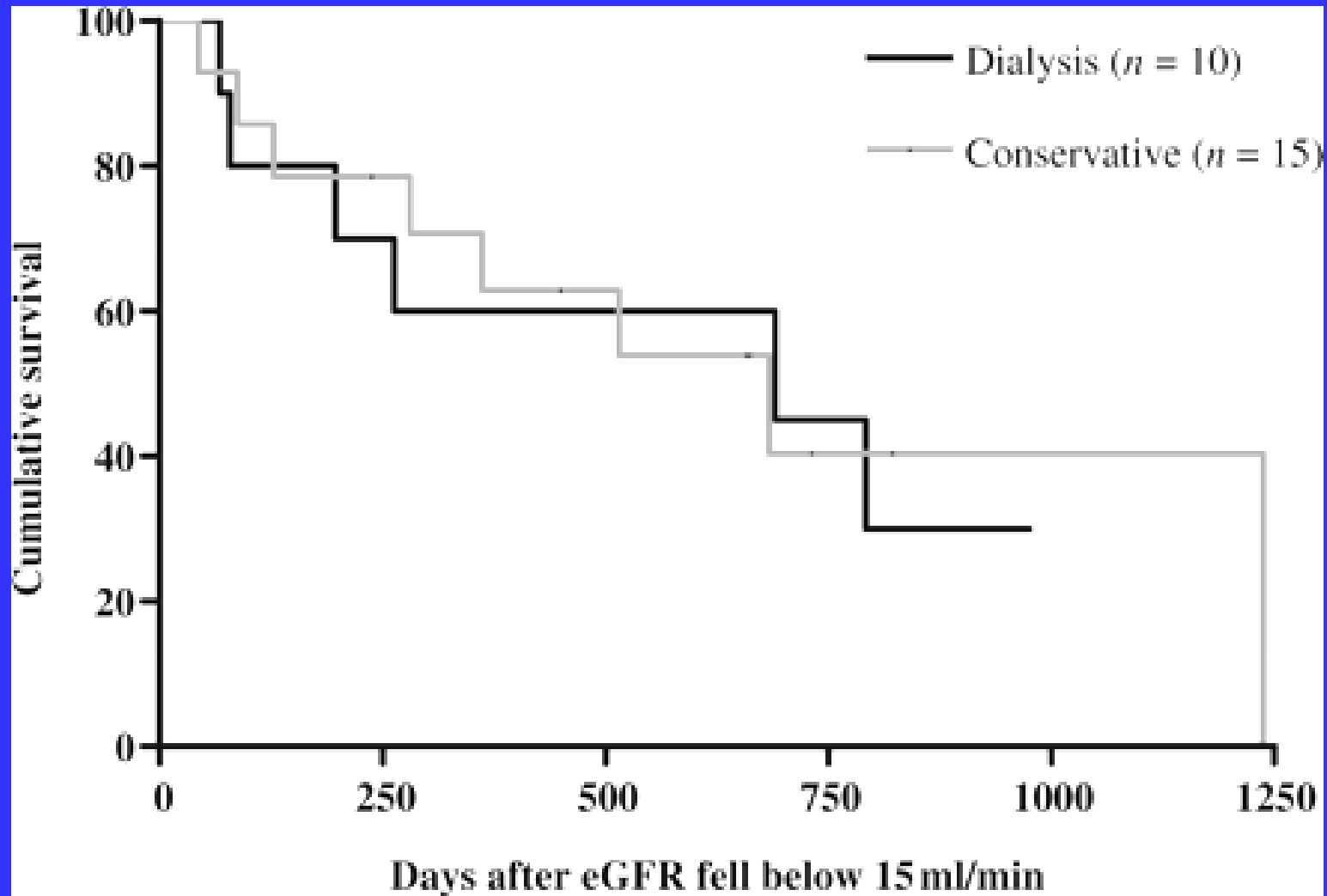
Dialysis or not ? A comparative study of survival of patients over 75 years with CKD Stage 5.

Murtagh FEM et al. *Neprol Dial Transplant*
2007;22:1955-1962

Survival

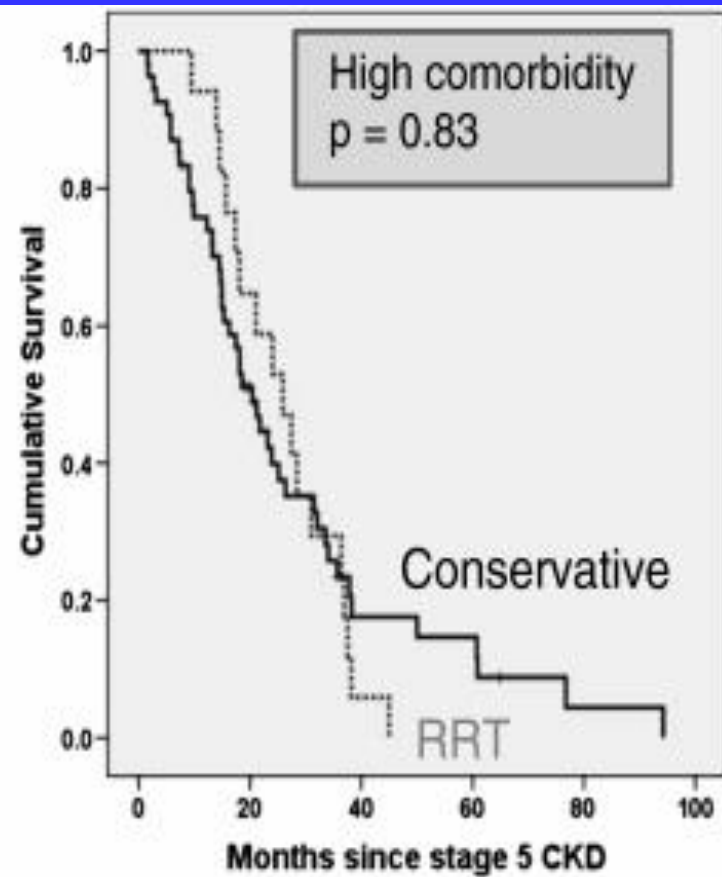
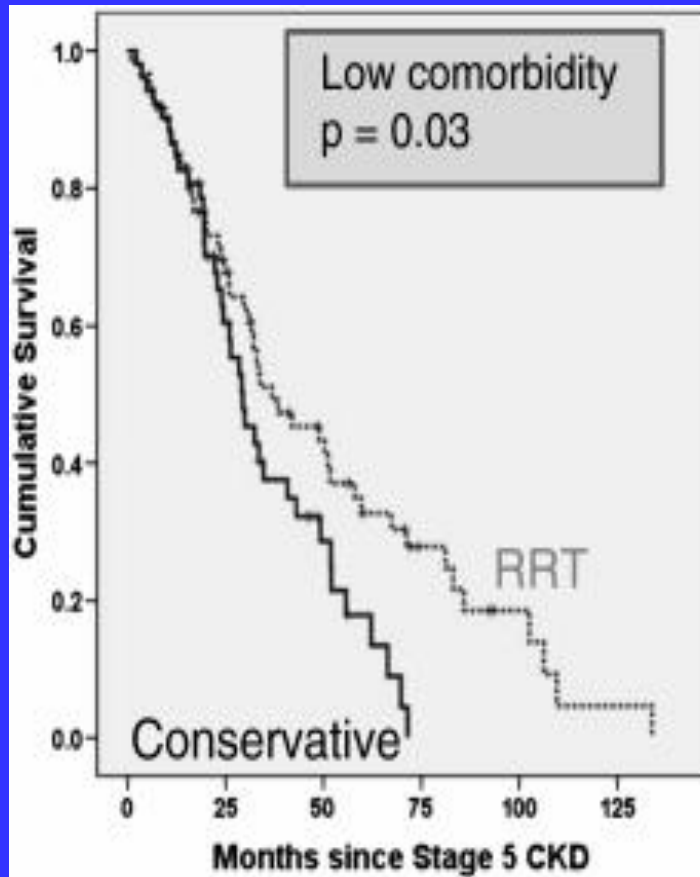


Survival benefit lost if Co-morbidities include IHD



RRT v Conservative

Chandra et al NDT Nov 2010



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^{*}*

CJASN 2015; 10 (2) : 260-268

In patients over 75 years with Ischaemic Heart Disease there was no survival advantage with dialysis compared to those who did not commence dialysis.

Carson et al CJASN 2009 went one step further...

For the dialysis cohort how did they spend their extra time ?

Approximately 80 % of the extra days survived were spent on dialysis or being hospitalised for complications of dialysis.

Carson et al CJASN 2009

Dialysis in Frail Elders — A Role for Palliative Care

Robert M. Arnold, M.D., and Mark L. Zeidel, M.D.



The NEW ENGLAND
JOURNAL of MEDICINE

Volume 361:1597-1598

[October 15, 2009](#)

Change in Functional Status after Initiation of Dialysis

3702 Nursing home residents mean age 73

Mean eGFR 10

Female 60%

Diabetes 68%

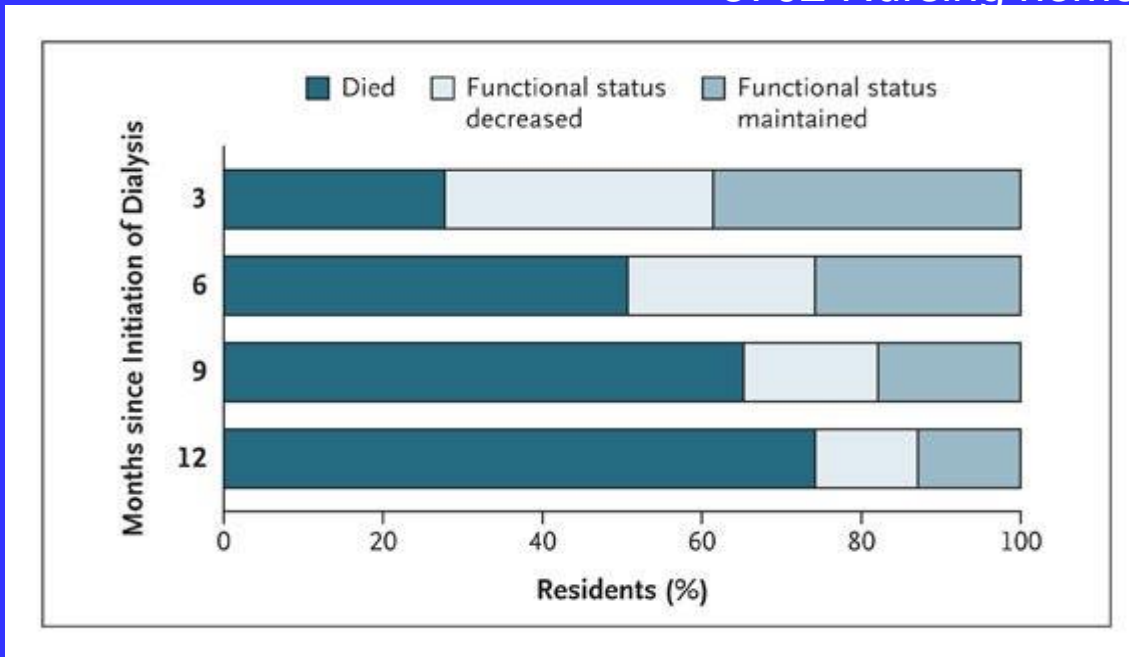
CHF 66%

CHD 44%

Cerebrovascular dis. 39%

Depression 35%

Dementia 22%



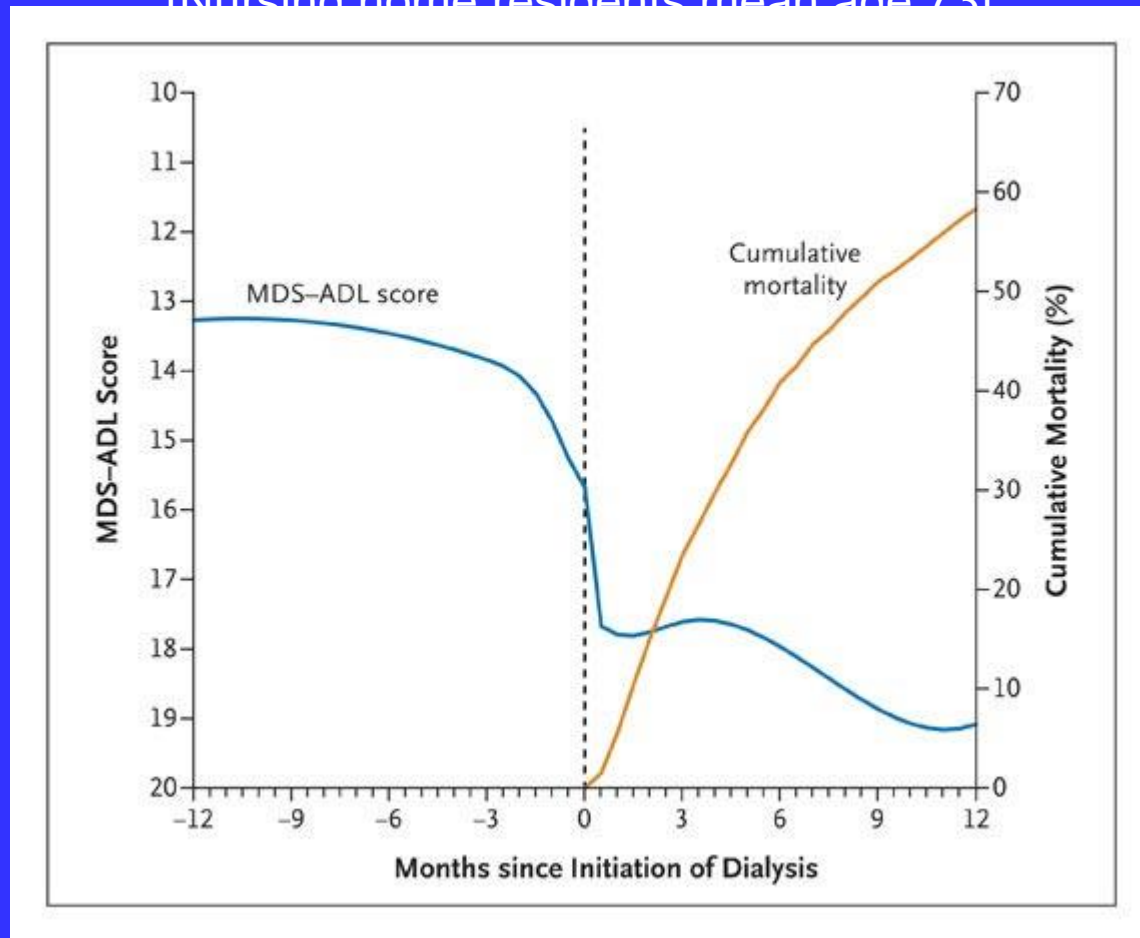
Kurella Tamura et al. 361 (16): 1539, October 15, 2009



The NEW ENGLAND
JOURNAL of MEDICINE

Smoothed Trajectory of Functional Status before and after the Initiation of Dialysis and Cumulative Mortality Rate

[Nursing home residents mean age 73]



Kurella Tamura et al. 361 (6): 539. October 15, 2009



The NEW ENGLAND
JOURNAL of MEDICINE

Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis

Wouter R. Verberne, A.B.M. Tom Geers,* Wilbert T. Jellema,* Hieronymus H. Vincent,* Johannes J.M. van Delden,[†] and Willem Jan W. Bos**

CJASN 2017

Survival advantage lost
if ≥ 80 years old.

2. Quality of Life

SF 36 scores compared to age/sex matched general population

SF36 domain	Dialysis group (n=134)	Supportive care group (n=45)
Physical functioning	↓	↓
Physical role functioning	↓	↓
Bodily pain	↓	↔
General health perceptions	↓	↔
Vitality	↓	↔
Social role functioning	↓	↓
Emotional role functioning	↓	↓
Mental health	↓	↔

3. Hospitalisations

In elderly patients on dialysis the rates of hospitalisation - 20-35 days per year.

Carson et al CJASN 2009

Rohrich et al NDT 1998

In elderly patients on a conservative pathway the rates of hospitalisation - 10 - 16 days per year.

Carson et al CJASN 2009

Wong et al Renal Failure 2007

4. Impact on carers

Median 56-70 hours of care per week.

Belasco et al AJKD 2006

All aspects of Quality of Life (QOL) affected.

Increasing carer burden with
increasing patient age and co-morbidities
and worsening functional status and QOL.

Belasco t al. *AJKD* 2006

Alvarez et al. *J Nephrology* 2004

Overall effect on the patient of dialysis

- Large change in routine
- Post dialysis fatigue and other symptoms.
- Travel to come to dialysis.
- Role of carers.

Much of this information was brought into guidelines for Nephrologists to help them in their decision making and advice to patients and families.

*Clinical Practice Guidelines on Shared
Decision-Making in the Appropriate
Initiation of and Withdrawal from Dialysis*

Renal Physicians Association of the USA 2010.

Recommendation No. 6

It is reasonable to consider forgoing dialysis for ... ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.

1. Those whose medical condition precludes the technical process of dialysis because the patient :

(a) is unable to co-operate (eg. Advanced Dementia)

(b) unstable medically (eg. Significant hypotension)

2. Another life-limiting illness – although this may be negotiated

3. Over 75 years

with 2 or more of the following statistically significant criteria predictive of very poor prognosis :

(a) Surprise question.

(b) High Co-morbidity Score

(c) Significantly impaired Functional status such as Karnofsky < 40,

(d) Severe chronic malnutrition (s. Albumin < 25.)

So if the recommendation to the patient that they may not do well on dialysis and that is reasonable to choose a non-dialysis pathway, the patient and the family will ask three questions to the Nephrologist.

- “If I don’t start dialysis what can you do for me ?”
- “How long do you think I will live if I don’t start dialysis ?”
- “What will happen to me during this time ?”

“So what can you do for me ?”

Conservative management of ESRD

This may be decided in consultation with a Nephrologist, or

The patient is not referred to a Nephrologist in the first place

What level of care occurs for this group ?

If this is being raised as an option :

What does a Conservative pathway mean ?

What is its content ?

Can we make predictions about their course ?

Challenge is
to ensure that this pathway of
management is not seen as “second best”
or inadequate

but is thorough, systematic and
evidenced-based

CKD conservative management

Not abandonment

CKD conservative management

Not simply transfer to Palliative Care

The care should be the best of the two disciplines

Renal Medicine

Blood Pressure

Calcium/Phosphate

Anaemia

Fluid balance

Palliative approach

Symptom management

Psychosocial support

Care of the dying

“How long do you think I will live
if I do not start dialysis ?”

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^{*}*

CJASN 2015; 10 (2) : 260-268

One-third of non-dialysis patients lived more than 12 months after eGFR fell below 10ml/min.

Median survival in Conservatively managed patients from time of modality choice = 18 months

Brown et al. (2015) = 16 months

Wong et al. = 23 months

Kwok et al (2016) = 16 months

Carson = 14 months

Murtagh = 18 months

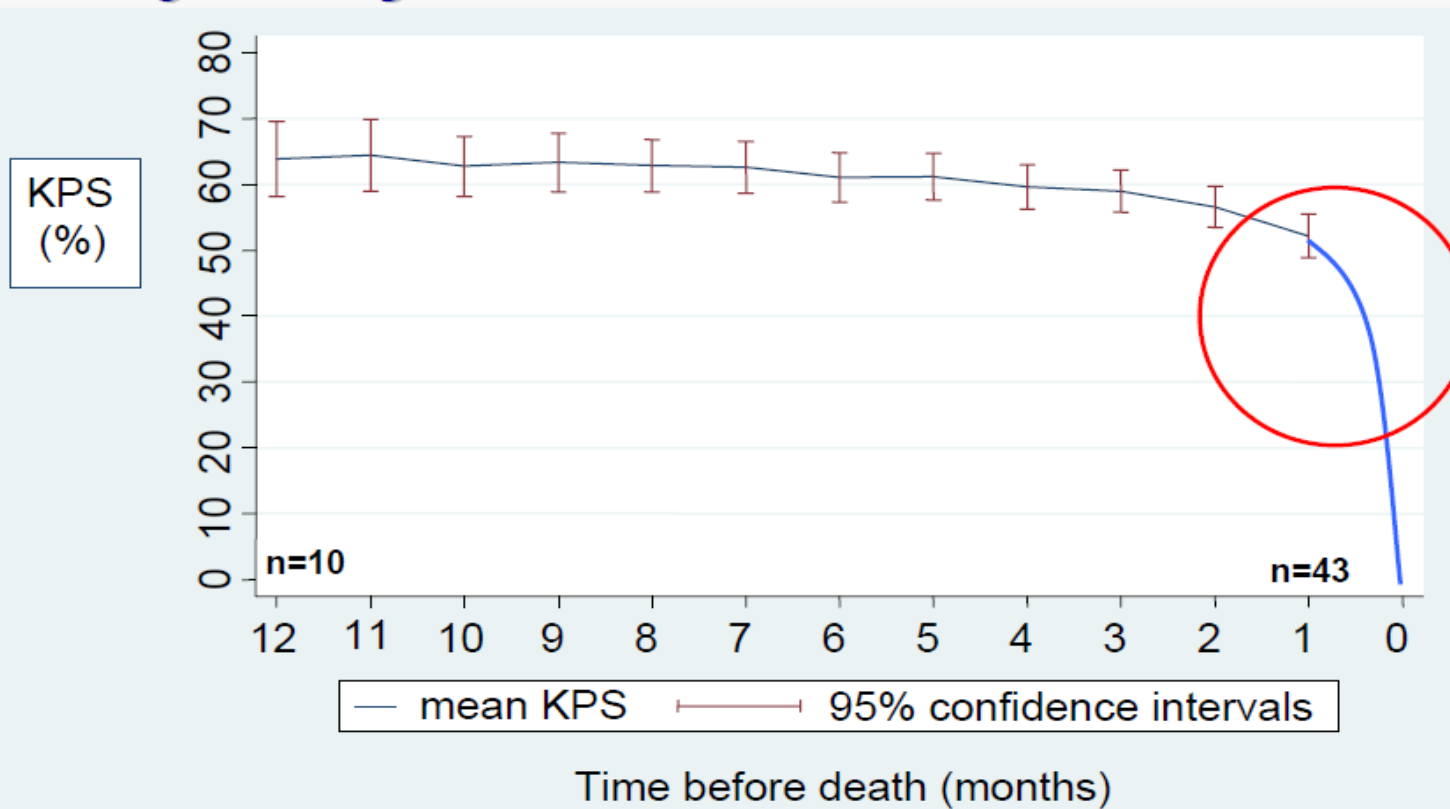
“What will happen to me during this time ?”

There is a modest, but growing body of literature of research on this cohort of patients.

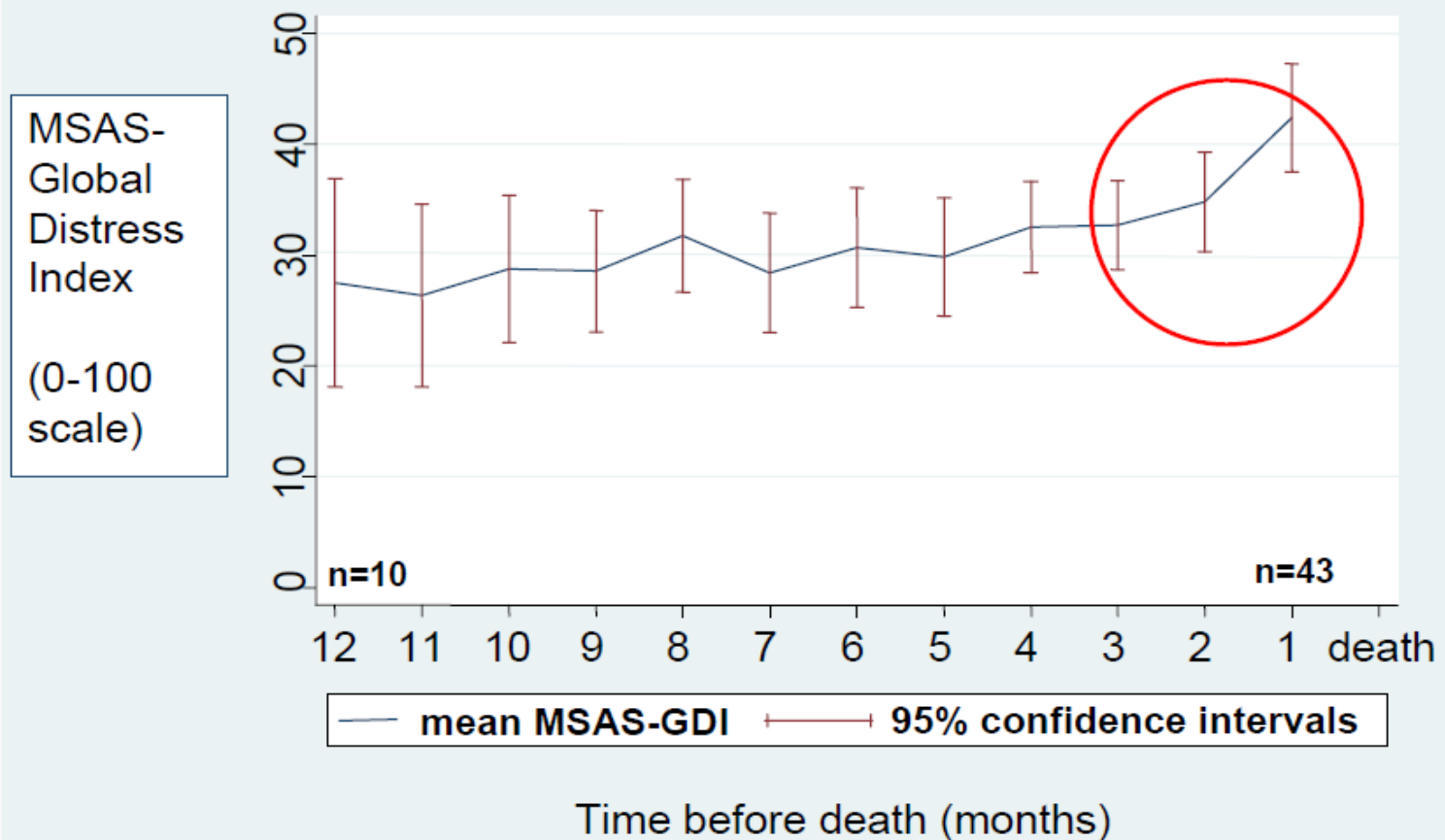
Longitudinal study of conservative stage 5 CKD

- **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)**

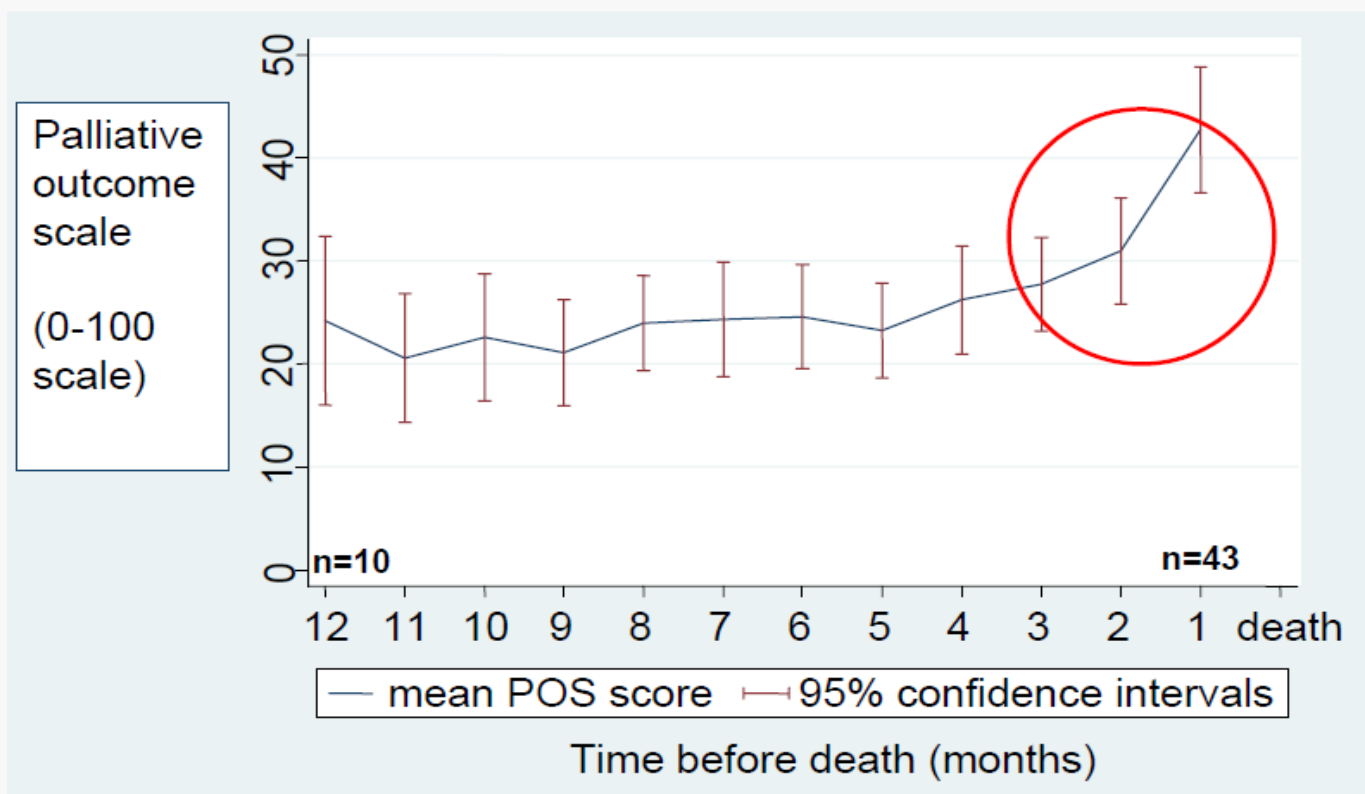
Trajectory of functional status:



Trajectory of symptom distress:



Trajectory of palliative needs:



Decision making and dialysis – a short summary

This requires a careful balancing of the benefits and burdens of dialysis for this individual patient.

It also requires a clear conversation by the Nephrologist with the patient about what dialysis means and what the patient should expect.

That conversation could focus
on two main things...

- Survivorship
- Overall effect on the patient

Survivorship

There is a growing body of evidence that for patients with ESKD who are 75 years or older with IHD there is no survivorship advantage in being on dialysis than being on a non-dialysis, conservative pathway.

Overall effect on the patient of dialysis

- Large change in routine
- Post dialysis fatigue and other symptoms.
- Travel to come to dialysis.
- Effect on carers.

As part of this conversation :

To raise the possibility of a non-dialysis pathway.

Symptom management

A 53 year old woman

- Type 2 Diabetes Mellitus
- Hypertension
- OA – mild
- ESKD – Diabetic Nephropathy
- HD 3/week for 5 years

- Shuffled in to the clinic room
- Head down
- No eye contact

“My legs move all through the night” –
Severe Restless Legs Syndrome - 2
years

“I itch all the time... often it becomes ferocious”

Severe uraemic pruritus – 3 years

“My feet and calves burn and get pins and needles – it is awful”

Severe diabetic peripheral neuropathy –
18 months

And sleep ?

“I don’t sleep... I doze in 5 minute lots...

“I sit on a chair and put my elbows on my knees to hold them still...

and I pray to die.”

What are the common symptoms associated with ESKD ?

The Prevalence of Symptoms in End-stage Renal Disease : A systematic Review

Murtagh FE et al. *Advances in Chronic Kidney Disease*
Vol 14, No 1 (January) 2007; pp 82-99

A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis

Murtagh FEM et al. *J Pall Med* 2007; 10(6) :1266-1276

The symptoms of patients with CKD stage 5 managed without dialysis.

Brennan FP et al. *Progress in Palliative Care* 2015; 23 (5): 267-273.

SYMPTOM PREVALENCE

Dialysis

Conservative

	Dialysis	Conservative
FATIGUE/TIREDNESS	71%	75%
PRURITUS	55%	74%
CONSTIPATION	53%	
ANOREXIA	49%	47%
PAIN	47%	53%
SLEEP DISTURBANCE	44%	42%
ANXIETY	38 %	
DYSPNEA	35 %	61%
NAUSEA	33 %	
RESTLESS LEGS	30 %	48 %
DEPRESSION	27 %	

- Symptoms are prevalent
- Symptoms are multiple
- Symptoms are burdensome

Symptoms interact
and compound each other.

Nocturnal :

U.Pruritus

RLS → Insomnia → Fatigue

Pain

Symptoms may derive from the co-morbidities

Symptom control is challenging

ESKD constrains the use of medication

Pharmacology in the context of CKD is complex

with the altered pharmacokinetics of most medications in renal impairment.

Multiple gaps in knowledge

Recommendations in published data occasionally conflict on the specific doses of medications to be used.

Principles of symptom management

1. Think of the cause(s).
2. Be meticulous
3. Principle of non-abandonment

Symptom measurement instruments

I-POS –S (Renal)

IPOS-Renal Patient Version



Patient name :
 Date (dd/mm/yyyy) :
 Patient number : (for staff use)

www.pos-pal.org

Q1. What have been your main problems or concerns over the past week??

1.
2.
3.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has **affected you over the past week?**

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sore or dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty Sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1.
2.
3.

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5. Have you been feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q8. Have you had as much information as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	None at all	Up to half a day wasted	More than half a day wasted		
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	On my own	With help from a friend or relative	With help from a member of staff		
Q11. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

FATIGUE

Complex and multifactorial

Anaemia - Hb best kept at 11-12

Electrolyte imbalance :

Hyper K

Hyper Ca

Hypo K

Hypo Ca

Hypo Mg

Hypo Na

Hypo PO₄

- Nutritional deficiency
- Depression
- Insomnia > Daytime somnolence
- Pain > deconditioning

Fatigue will have an effect on multiple other aspects for the patient :

- QOL
- ADLs
- Need for transport assistance
- Frustration

Management

- Optimise Dialysis
- Correct reversible causes
- Physiotherapy – gentle exercise
- Sleep Hygiene
- Social Supports

PAIN

Epidemiology of pain in CKD

Dialysis patients – 58 %

Mean weighted prevalence over 36 studies

Davison S, Koncicki H, Brennan F. Pain in Chronic Kidney Disease : A Scoping Review. *Seminars in Dialysis* 2014; 27(2): 188-204.

49 % reported the pain as
moderate to severe

Data on conservatively managed patients
is more limited
but shows similar prevalence and severity
figures.

Murtagh FEM et al. A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis. *J Pall Med* (2007) 10;6:1266-1276.

Brennan FP. Et al. Symptoms in patients with CKD managed without dialysis. *Progress in Palliative Care* 2015 (in Press)

Impact on function and QOL

Impact on QOL

Davison (2002)

69 dialysis patients

62% stated that pain interfered with their ability to participate and enjoy recreational activities.

51 % stated that pain caused them
“extreme suffering”

41 % stated that pain caused them to consider ceasing Dialysis

Positive correlation with depression

Davison S, Jhangri GS. *J Pain Symptom Management*
2005; 30(5): 465-473

Causes of Pain

ESRD
and its treatment

Co-morbidities

1. Pain related to the disease:

- Polycystic Kidney Disease
- Renal Bone Disease
- Amyloid – including Carpal Tunnel Syndrome
- Calciphylaxis

2. Pain secondary to treatment :

- PD pts with recurrent abdominal pain
- AV Fistulae > 'Steal syndrome'
- Cramps
- Intradialytic headaches

3. Pain related to co-morbidities

- OA
- Diabetic peripheral neuropathy
- PVD / IHD

Pain etiquette

- ENQUIRE REGULARLY
- RESPOND COMPASSIONATELY
- TREAT COMPETENTLY
- REFER WISELY

Pain management in patients with CKD

The traditional approach to the pharmacological management of pain has been to use the WHO Analgesic Ladder.

Certainly, the WHO Ladder
has been validated in the context of ESKD
and it remains a very useful construct.

Is an approach based on the WHO
Analgesic Ladder the most appropriate
approach in the specific context of CKD ?

Towards a strategic approach to pain
management
in patients with CKD

1. There are few studies
examining pain management
in the specific context of CKD

2. There are international evidence based guidelines and consensus statements on pain management of specific pain syndromes for the whole population.

- Osteoarthritis
- Painful diabetic peripheral neuropathy
- Cancer pain

3. There is an increasing, although not complete, understanding of the pharmacology of analgesic medications in the context of CKD and their dialysability

These recommendations could be filtered through the known pharmacology of medications in the context CKD and their dialysability

Pain syndrome



Evidence based Guidelines and Consensus Statements



Pharmacokinetics/Pharmacodynamics



Pain management for patients in the context of CKD

Example -

Painful diabetic peripheral neuropathy

1. Currently there are no evidence-based or consensus guidelines on the management of painful DPN in patients with CKD.

“Clinical evidence regarding the effects of [analgesic agents] to treat DPN in patients on dialysis therapy and those with CKD Stage 4-5 is virtually non-existent.”

Pop- Busui R et al. The Management of Diabetic Neuropathy in CKD. *Am J Kid Dis* 2010; 55(2): 365-385.

2. There is a significant body of literature on the management of painful DPN.

That literature includes several international evidence based guidelines.

Evidence-based guideline : Treatment of painful diabetic neuropathy. Report of the American Association of Neurology et al.

Bril V et al. *Neurology* 2011; 76: 1758-1765.

Level A Evidence - Pregabalin

Analgesics in Chronic Kidney Disease

Step 1

Paracetamol

No dose adjustment = 1g qid

“It is considered the non-narcotic analgesic of choice for mild-moderate pain in CKD patients.”

Davison S, Ferro CJ. Management of Pain in CKD.
Progress in Palliative Care 2009; 17: 186-195.

Step 2

Tramadol

Need for dose adjustment

If on a Conservative pathway
eGFR < 15
or Dialysis

Tramadol 50mg bd (maximum)

If on Conservative pathway eGFR 15-30

Commence 50mg bd

Maximum 100mg bd

General concerns regarding Tramadol

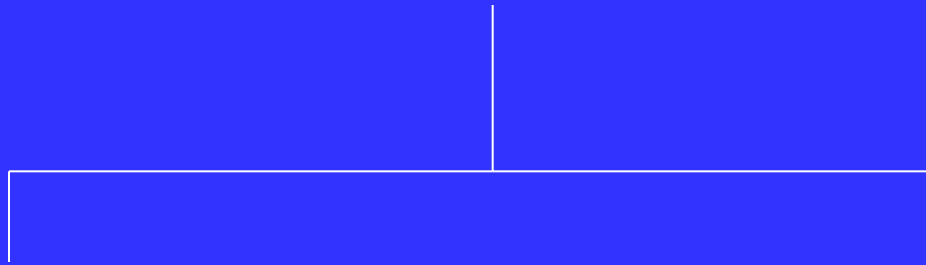
Codeine

Metabolised in Liver

Codeine

Morphine

Norcodeine



Reports of :
profound hypotension
CNS and
Respiratory depression

“Not recommended in CKD.”

Davison S et al. *Seminars in Dialysis* 2014; 27(2): 188-204

Morphine

Morphine

Hepatic metabolism

M-3-G

M-6-G

Kidneys

Morphine is not recommended in CKD

Davison S et al. *Seminars in Dialysis* 2014; 27(2): 188-204

Oxycodone

“Overall consensus is that Oxycodone is reasonably safe to use in CKD if monitored carefully.”

Davison S et al. *Seminars in Dialysis* 2014; 27(2): 188-204

Fentanyl

- Metabolised in Liver
- Inactive metabolites
- 5-10 % excreted unchanged renally
- Fentanyl is not dialysed (HD/PD)

Fentanyl is safe to use at standard doses

- should monitor carefully.

Davison S et al. *Seminars in Dialysis* 2014; 27(2): 188-204

Buprenorphine

Buprenorphine

Buprenorphine – 3 – Glucuronide
(B-3-G)

Norbuprenorphine
(NorB)

Both accumulate in CKD

B-3-G is inactive ; NorB has minor analgesic quality

“Buprenorphine may be given in standard doses to patients with CKD. Generally considered safe for use in CKD if monitored carefully.”

Davison S et al. *Seminars in Dialysis* 2014; 27(2): 188-204

Methadone

- Metabolised in liver
- Excreted mainly in the feces. Some renal excretion of Methadone and its metabolites
- Not dialysed
- Safe to use, but requires skill in dosing regimen – specialist use.

*The hand that writes the opioid must also
write the laxative*

RESTLESS LEGS SYNDROME

Definition

1. An urge to move the limbs, usually associated with paresthesia/dysaesthesia
2. Motor Restlessness
3. Symptoms exclusively while at rest, with relief (completely or partially) with movement.
4. Symptoms worse at night.
5. Cannot be solely attributed to another cause.

Not all ESKD patients
with a disturbance of their legs
have Restless Legs Syndrome.

Differential diagnosis

- Leg cramps
- Peripheral neuropathy
- Osteoarthritis
- Pruritus
- Akathisia

Associations

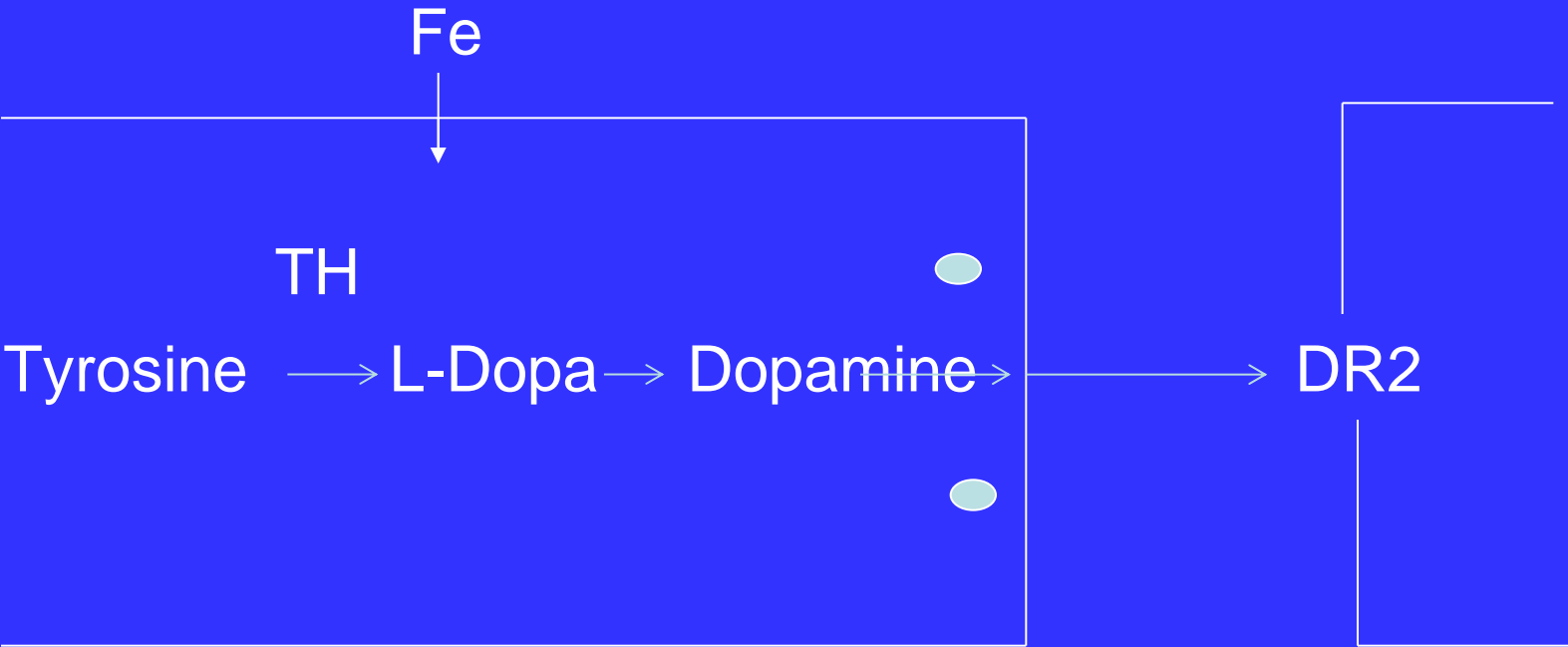
Sleep disturbance

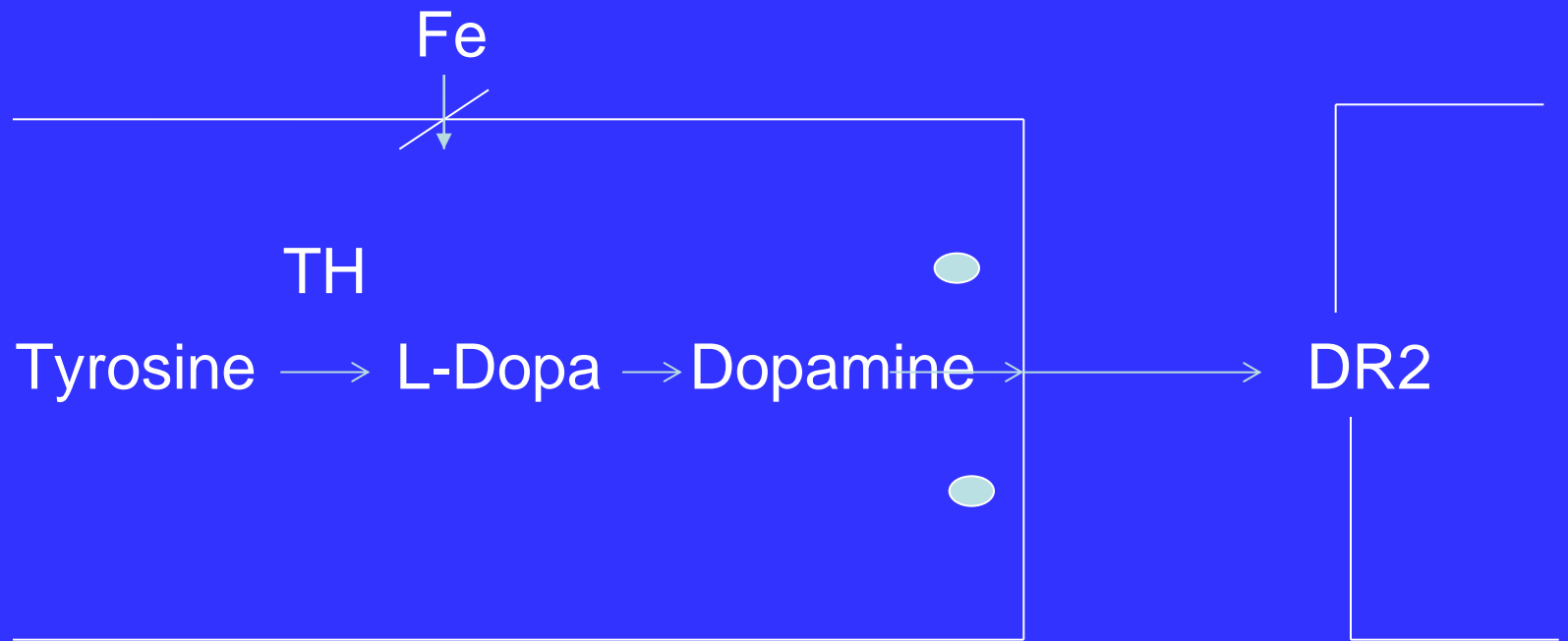
Daytime somnolence

Premature cessation of dialysis sessions

- Sleep disturbance
- Daytime somnolence
- Premature cessation of dialysis sessions
- Reduced QOL
- Hypertension
- New CVS events
- Mortality

Mechanism is not completely understood





Management

Dopamine agonists

Non-Ergot Dopamine Agonists (Pramipexole, Ropinirole, Rotigotine)

Gabapentin

Two RCTs have shown efficacy for Gabapentin in the treatment of RLS in Dialysis patients

- Study A – Placebo controlled – Thorp et al (2001)
- Study B – Gabapentin compared to Levodopa – Micozkadioglu et al (2004)

On Dialysis

Gabapentin 100mg after each Dialysis
and titrating to effect

**On conservative management with
eGFR < 15**

Gabapentin 100mg every second night
and titrating to effect

**On conservative management with
eGFR > 15**

Gabapentin 100mg nocte
and titrating to effect

Iron infusions – temporary benefit

IVI 1000mg Iron Dextran

Statistically improved RLS over placebo.
Effect faded at 4 weeks.

Giannaki CD. *BMC Nephrol* 2013; 14: 194.

Intradialytic exercise

Giannaki CD et al. *BMC Nephrol* 2013; 14: 194.

International Guidelines

European Federation of Neurological Societies (2012)

International RLS Study Group (2013)

“The use of a dopamine-receptor agonist or a [Gabapentinoid] is recommended as the first line treatment of RLS...for most patients...”

Garcia-Borreguero D et al. International RLS Study Group.
Sleep Medicine 2013; 14: 675-684.

URAEMIC PRURITUS

Not everyone with ESKD and itch
has uraemic pruritus

At the point of assessment always consider a differential diagnosis of the pruritus.

The pathogenesis of pruritus generally and uraemic pruritus in particular remains elusive

C Fibres

5 - 10 % of the C fibres are itch sensitive

Of the C Fibres that are itch-sensitive :

10 % are Histamine-dependent

90 % are Histamine-independent

Davidson S. *J Neuroscience* 2007;27: 10007-14

Nainer B. *J Neurophysiology* 2008;100: 2062-9.

Myth 1

That all itch is histamine mediated

Myth 2

That the best first line medication for pruritus of whatever cause are Anti-Histamines

Almost certainly uraemic pruritus
is not histamine related

Pathogenesis of UP

Multiple theories, conflicting findings

Adequacy of dialysis

Dialysis adequacy (as measured by Kt/V)
did not correlate with the frequency of UP
in large epidemiological studies

Pisoni RL, Wikstrom B et al. *Neprol Dial Transplant*
2006; 21: 3495-3505.

Narita et al. *Kidney Int* 2006;69; 1626-32.

Duque et al. *Clin Nephrology* 2006; 66: 184-191.

Xerosis

Dry skin is an association
and exacerbating factor
but not a primary cause

Szepietowski JC. *Nephrol Dial Transplant* 2004; 19: 2709-2712.

HyperParathyroidism

- There is no correlation between PTH levels and UP
- PTH itself is not pruritogenic

Calcium

Inconsistent findings on s.Calcium and UP

“Despite this vast array of possible explanations, none consistently have been demonstrated to be the underlying cause of pruritus associated with CKD. Large epidemiological studies ultimately may facilitate our understanding of the elusive pathophysiological process of this distressing symptom.”

Patel TS et al. *Am J Kidney* 2007; 50(1): 11-20.

What therapies have the strongest
foundation in evidence – based practice ?

- Topical preparations
- Oral medications
- UV- B Therapy

Topical preparations

Moisturisers

Capsaisin

Breneman DL et al. *J Am Acad Dermatol* 1992; 26: 91-94. Tarng D-C et al. *Nephron* 1996; 72: 617-622; Maklough A. *Iranian J Kid Dis* 2010;4(2): 137-140.

Difficulty with Capsaisin is that it causes a burning feeling on the skin - 0.025 % cream.

Gabapentin

Gabapentin for uremic pruritus in hemodialysis patients : a qualitative systematic review.

Lau T et al. *Canadian J Kidney Health and Disease* 2016; 3: 14.

“Our review supports a trial of Gabapentin for the management of Uraemic Pruritus in hemodialysis patients refractory to antihistamines and/or emollients. The results should be interpreted cautiously due to the lower quality of included studies. We recommend a starting dose of 100mg after hemodialysis to minimize adverse events...”

Treatment of Uremic Pruritus : A Systematic Review.

Simonsen E et al. *Am J Kid Dis* 2017. Article in Press.

“The main finding...is that with exception of the evidence for gabapentin, there remains considerable uncertainty about effective treatments for this important and burdensome symptom...”

Pregabalin

Several prospective cohort studies showed efficacy.

Aperis. *J Renal Care* 2010; 36(4): 180-185; Shavit L. *J Pain Symptom Management* 2013; 45(4): 776-781.

Evening Primrose Oil

Chen YC et al. *Am J Kid Dis* 2006; 48: 69-76

Gamma Linolenic Acid (GLA)

Essential Fatty Acids (EFA)

n- 6 EFA

Linolenic Acid (LA)



Gamma-Linolenic Acid (GLA)



DGLA



Arachidonic Acid



Adrenic Acid



Docosapentaenoic Acid

n-EFA

Linolenic Acid (LA)



Gamma-Linolenic Acid (GLA)



DGLA



Arachidonic Acid (AA)

PGE2



Leukotriene B4



Adrenic Acid



Docosapentaenoic Acid

- PGE 2 is pro-inflammatory
- Leukotriene B4 is very pruritogenic

n-EFA

Linolenic Acid (LA)



Gamma-Linolenic Acid (GLA)



DGLA

PGE1



15 OH DGLA



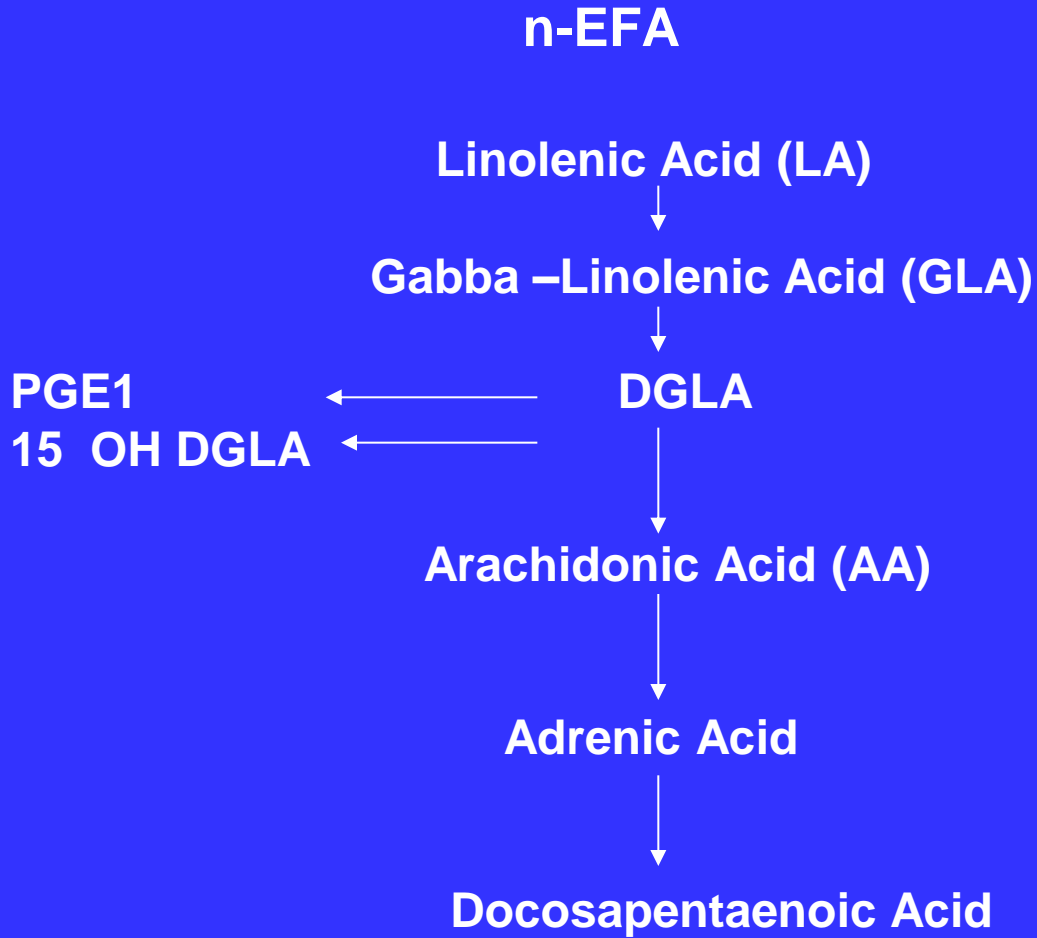
Arachidonic Acid (AA)



Adrenic Acid



Docosapentaenoic Acid



PGE1 and 15 OH DGLA have an
anti-inflammatory/ anti-pruritic effect

So supplementing the Gamma-Linolenic Acid (GLA) has an anti-inflammatory/ anti-itch effect...

100mg capsules 1-2 bd

Sertraline (SSRI)

Shakiba M et al. *Int J Nephrology* 2012;
Article ID 363901; 1-5

- Before and after trial of 19 HD patients.
- 50mg daily for 4 months.
- The difference in the grade of pruritus before and after sertraline was significant.

Thalidomide 100mg nocte

Silva SR. *Nephron* 1994; 67(3): 270-273

UV-B Therapy

Uraemic pruritus summary

Moisturisers plus

1. Gabapentin/Pregabalin

2. Evening Primrose Oil

3. UV – B therapy

4. Others.

Note - Anti-histamines do not help

INSOMNIA

This may be the product of multiple other symptoms

- Pain
- Uraemic Pruritis
- Cramps
- RLS
- Periodic Leg Movement Disorder
- Sleep Apnea

In a study of 254 HD patients
there was a 57 % prevalence of moderate to
severe OSA.

Nicholl DD et al. *Chest* 2012; 141: 1422-1430.

- Treat the cause
- Treat the symptom

General measures

- No caffeine after lunchtime
- No alcohol at night
- No smoking at night
- Temazepam 10-20mg nocte

Specific measures

If suspicious of Sleep Apnea –

Formal Sleep Study

Gastrointestinal symptoms

ANOREXIA

Multifactorial

- Nausea
- Dry mouth
- Altered taste
- Delayed gastric emptying
- Depression
- Uraemia
- Inadequate dialysis
- Abdominal discomfort and swelling from CAPD

- Patients on Dialysis require 2 x protein of the non-dialysis patient.
- Chronic Protein Energy Malnutrition is common

Management

- Attempt to reverse the reversible causes
- Renal Dietician Review

NAUSEA

Look for the cause (s)

- Uraemia → CTZ zone
- Delayed Gastric emptying
- Concurrent medications
- Constipation

Treat the symptom :

Maxalon 5mg – 10mg tds

Haloperidol 0.5mg bd

Cyclizine 25- 50mg tds

Ondansetron – very constipating

A 72 y.o. man.

- ESKD – on Home HD
- Main symptom is nausea.
- Commenced on Metoclopramide 10mg tds.
- Two weeks later reports nausea well controlled.
- “By the way, doctor, my legs keep moving at night.” - Restless Legs ++



Depression/Anxiety

Slides prepared, with acknowledgement, to Dr Kirsty Morris, Liaison Psychiatrist, Royal Prince Alfred Hospital, Sydney

Depression

Especially chronic kidney disease

20% of patients with CKD have depression

CKD 1 - 4	21.5%
Dialysis	22.8%

Palmer et al 2013

The diagnosis of depression in CKD

This is challenging given that several of the DSM criteria for depression are also experienced by patients with CKD

Fatigue, anorexia, insomnia

“It is recommended that the diagnosis of depression in a patient with CKD should rely more heavily on psychological features such as loss of enjoyment in life, guilt, loss of self-esteem, hopelessness and suicidal ideation.”

Bautovich A et al. *Aust NZ J Psychiatry* 2014; 48(6): 530-541

Why is depression in ESKD important?

- Increased mortality rates from all causes¹
- Reduced compliance^{2,3,4}
- Withdrawal from treatment^{5,6}
- More symptoms - fatigue, cognitive, pain, sleep, sexual^{7,8}
- Reduced quality of life⁹
- More disability¹⁰

- 1.Palmer et al 2013
- 2.Kaveh and Kimmel 2001
- 3.Koo et al 2003
- 4.Leggat et al 2005
- 5.Lacson et al 2012
- 6.McDade-Montez et al 2006
- 7.Katon et al 2011
- 8.Soni et al 2010
- 9.Preljevic et al 2013
- 10.Stein et al 2010

Suicide

Suicide, suicidal ideation and suicide attempts probably more frequent in dialysis patients

- Risks^{2,3}: older age, male, medical comorbidity, substance use disorder, depression/anxiety,? ↓QOL^{4,5}

- Pompili et al 2013
- 2.Bronisch T and Wittchen H 1994
- 3.Kurella M et al 2005
- 4.Haenel et al 1980
- 5.Chen C et al 2010

“Unfortunately, despite these associations (between CKD and depression and depression and poor outcomes) and the increasingly available evidence, clinicians remain cautious when managing depression in those with CKD, and rates of detection and treatment remain very low.”

Bautovich A et al. *Aust NZ J Psychiatry* 2014; 48(6): 530-541.

Vulnerable periods for developing depression in CKD

- First year of treatment
- Failing transplant
- Non-listing for transplant¹

Not everyone with CKD gets depressed

Treatment

There are very few studies

There is only one RCT of an antidepressant medication in CKD patients

Blumenfield et al 1997

Antidepressants

- Evidence is lacking
- Think about pharmacokinetics, potential interactions, and side effect profile
- Reasonable choices include citalopram, sertraline, venlafaxine, amitriptyline, mirtazapine

Other biological treatments

- ECT
 - Case reports of good response in patients with CKD^{1,2}
- Exercise therapy^{3,4}
- Changes in dialysis regimen^{5,6} - insufficient evidence

1. Varghese et al 2006
2. Williams and Ostroff 2005
3. Ouzoni et al 2009
4. Kouidi et al 2010
5. Hedayati and Finkelstien 2009
6. Jaber et al 2010

Psychosocial treatments

- Evidence for CBT in chronic medical illness
 - Limited evidence in ESKD population^{1,2}
 - Role of internet in treatment³
- Social support^{4,5,6}
- Family/marital counselling^{4,5}

- 1. Cukor 2007
- 2. Duarte et al 2009
- 3. <https://moedavm.anu.edu.au/welcome>
- 4. Cohen et al 2007
- 5. Hedayati et al 2012
- 6. Patel 2005

A 53 year old woman

- Type 2 Diabetes Mellitus
- Hypertension
- OA – mild
- ESKD – Diabetic Nephropathy
- HD 3/week for 5 years

Referred to clinic because of extreme :

1. Uraemic Pruritus
2. Restless Legs Syndrome
3. Diabetic PN
3. Very poor sleep

Gabapentin commenced for all conditions at 200mg at the completion of each dialysis.

- Complete cessation of all symptoms and a markedly improved sleep
- Sleeping “*the best I have for a long time.*”

Conclusion

- Symptom management is an important arm of management.
- Symptoms are prevalent and multiple

Be curious and reactive
rather than passive and nihilistic

- Be meticulous
- Symptom relief may have a significant impact of patients' Hr QOL

Advance Care Planning

What is an Advance Care Plan ?

A message :

“To my future doctors...”

Why is Advance Care Planning
important in Nephrology ?

Given the rising numbers of patients with ESRD who are elderly with co-morbidities

There will an increasing cohort of patients who will, at some point in their illness, become incompetent and not able to make their own medical decisions

A significant body of literature exists in
Renal Medicine on this subject

The majority of Dialysis patients report that they have never had a discussion with their Nephrologist about circumstances in which Dialysis should be ceased.

Cohen LM et al. Denying the dying. *Psychosomatics* 1997;38:27-34

Most patients would welcome a discussion
of future plans

Tulsky JA et al. *Ann Intern Med* 1994;120:567-573.

Many dialysis patients do not know they have an option to withdraw from dialysis

Cohen LM, Germain M, Woods At et al. *Psychosomatics* (1993);
34:395-401

Dialysis patients expect Nephrologists to initiate these discussions

Fine A et al. *Perit Dialysis Int* 2005;25:269-273

Dialysis patients would prefer that their family would be present and be involved in these discussions.

Hines SC et al. *Ann Intern Med* 1999;130:825-828.

Both :

- Patient's family , and
- Patient's clinicians

consistently over- estimate the patient's true desires to continue dialysis in the event of Dementia, metastatic malignancy

Pruchno RA et al. *Med Decision Making* 2006; 26 :112-121

Miura SH et al. *Am J Kid Dis* (2006);47(1):122-130

Barriers to ACP

- Patient related
- Physician - related

Patient-related

- Inadequate understanding of ACP
- Belief that it is the Nephrologist's responsibility to raise the subject
- Reluctance to discuss death
- View that ACP are unnecessary because one's family "will know what to do when the time comes"
- Perception that ACP will not be followed

Barriers to ACP

Patient/Family :

- May not be aware of the serious nature of their illness.

Physician related

- Lack of training in these discussions
- Time constraints
- Lack of understanding of what Palliative Care/ a palliative approach would involve
- Belief that a ACP discussion will destroy hope
- Belief that patients/families do not want these discussions

Davison S. *Progress in Palliative Medicine* 2009;17:4: 170-178

Barriers to ACP

Clinicians :

Thought to be too emotionally draining

When ACP are done -- what is the experience of Australian Nephrologists ?

Clinicians' perspectives on Advance Care Planning for Patients with CKD in Australia : An Interview Study.

Sellars M et al. *Am J Kid Dis* 2017 (In Press)

Nephrologists found ACP conversations rewarding because they empowered patients...

*Clinicians became more comfortable
introducing and discussing
ACP following experience with repeated
ACP discussions...*

Nephrologists “found that ACP conversations...exposed personal and professional vulnerabilities [in themselves]...”

1. Lack of training

“In my opinion the biggest barrier is healthcare professionals not knowing how to have the conversation.”

Dr. E. Stallworthy, Nephrologist
Renal Supportive Care Master Class
Sydney, 2015.

2. Lack of resources

3. Pressure on Nephrologists when there is an inconsistency between ACP and family wishes.

And for patients ?

Hope

Hope and advance care planning in patients with end stage renal disease : qualitative interview study

Davison, SN, Simpson C. BMJ (2006); 1(5): 1023-1028.

Providing realistic information and a discussion about the future does not destroy hope

Indeed, such discussions can enhance a sense of hope

“by providing information early in the illness that focuses on the impact on daily life, empowering patients and enhancing relationships with staff and loved ones.”

“...unaddressed fears about the future and a lack of preparation of what lay up ahead were constant threats to hope.”

Are there Recommendations
for ACP in Nephrology ?

KDIGO

Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison¹, Adeera Levin², Alvin H. Moss³, Vivekanand Jha^{4,5}, Edwina A. Brown⁶, Frank Brennan⁷, Fliss E.M. Murtagh⁸, Saraladevi Naicker⁹, Michael J. Germain¹⁰, Donal J. O'Donoghue¹¹, Rachael L. Morton^{12,13} and Gregorio T. Obrador¹⁴

Recommended Advance Care Planning

*Clinical Practice Guidelines on Shared
Decision-Making in the Appropriate
Initiation of and Withdrawal from Dialysis*

Renal Physicians Association of the USA 2010.

The treating Nephrology team should engage in advance care planning.

These discussions should start early in the disease trajectory and should include discussions about health states in which patients would want to withhold or withdrawal from dialysis.

Australia and New Zealand

Review

Renal supportive and palliative care: position statement

SU CRAIL, ROB WALKER and MARK BROWN FOR THE RENAL SUPPORTIVE CARE WORKING GROUP*

Reviews

ANZSN Renal Supportive Care Guidelines 2013**THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS**

Mark A Brown¹ and Susan M Crail², ¹Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, and ²Central and North Adelaide Renal and Transplantation Service, Adelaide, South Australia, Australia

2 For dialysis or transplantation.

3 *Indeterminate* – that group for whom the treating nephrologist and the patient are unable to come to a clear decision. For people in this group, seeking a second opinion and ideally, discussing the case at a multidisciplinary team meeting (similar to those discussions surrounding acceptance onto the transplant waiting list) are paths to follow.

A very important principle is that these planning discussions need to take place early in the course of a patient's

How to facilitate ACP discussions ?

What does the evidence indicate is the best intervention ?

Advance Care Planning for Adults With CKD: A Systematic Integrative Review

Tim Lockett, PhD,^{1,2,3} Marcus Sellars, PGDipPsych,⁴ Jennifer Tieman, PhD,⁵ Carol A. Pollock, MBBS, FRACP, PhD,^{6,7} William Silvester, MBBS, FRACP,⁴ Phyllis N. Butow, M Clin Psych, PhD,⁸ Karen M. Detering, MBBS, FRACP, MH Ethics,⁴ Frank Brennan, MBBS, FRACP,⁹ and Josephine M. Clayton, MBBS, FRACP, PhD^{1,6,10}

Background: Recent clinical practice guidelines have highlighted the importance of advance care planning (ACP) for improving end-of-life care for people with chronic kidney disease (CKD).

Study Design: We conducted a systematic integrative review of the literature to inform future ACP practice and research in CKD, searching electronic databases in April 2013. Synthesis used narrative methods.

Setting & Population: We focused on adults with a primary diagnosis of CKD in any setting.

Selection Criteria for Studies: We included studies of any design, quantitative or qualitative.

- Most studies on ACP in CKD were descriptive and addressed patient's preferences for and attitude to ACP.
- Few intervention studies with limited outcomes

Accompanying Editorial

“While we await more definitive study of this issue, we can only hope that clinical nephrologists realize the importance of ACP and engage in these conversations with their patients and families.”

Holley J, Davison S. *Am J Kid Dis* 2014; 63(5): 739-740.

There is a problem :

- Clear recommendations from professional bodies within nephrology.
- Known barriers including absence of professional training.
- Limited intervention studies.
- Limited uptake.

- Clear recommendations from professional bodies within nephrology.
- ***Known barriers including absence of professional training.***
- Limited intervention studies.
- Limited uptake.

The Auckland model

Leadership within the
Auckland District Health Board
Department of Nephrology

to train Nephrologists, Renal Nurses and
Social Workers.

- Clear recommendations from professional bodies within nephrology.
- Known barriers including absence of professional training.
- ***Limited intervention studies.***
- Limited uptake.

RCT of nurse facilitated ACP
in dialysis patient/surrogate decision maker
dyads.

Each arm had 210 patients.

Followed at 12 months.

Song MK et al. *Am J Kid Dis* 2015 June 30

For those who had received the intervention there were statistical improvements in :

- Agreement between patient and their surrogate on EOL goals of care
- Surrogate confidence in decision making.
- Where the patient died surrogates had less anxiety, depression and post-traumatic stress than the controls.

How to do an ACP in Nephrology.

1. Which patients ?

Could be all dialysis patients, or

Those patients with a limited prognosis according to age, co-morbidities, frailty.

2. Patient must be competent

Participants

The Nephrologist should initiate and lead these discussions.

Involvement of other members of the Multi-disciplinary team

3. Content

A. Name a person or persons close to you to make a decision for you.

A. “If I were to become seriously and irreversibly ill and not able to make a medical decision I would like you to turn to my”

B. Tell the future doctors what you would like or not like done to you.

B. “If I were to become seriously and irreversibly ill and not able to make a medical decision I would like you to do / not do the following things :”

How realistic is the patient and their family ?

- Expectations of Dialysis
- Expectations of CPR

Throughout this process the Nephrologist
should guide the patient and the family
- not simply saying :

“These are your options, you decide”

but rather

Giving clear medical recommendations

Once raised, this conversation continues

Care of the dying patient with ESKD

ESKD patients may die :

- Having been on dialysis
- Never having been on dialysis

Patients with ESKD on dialysis may die in many different ways

1. Sudden death

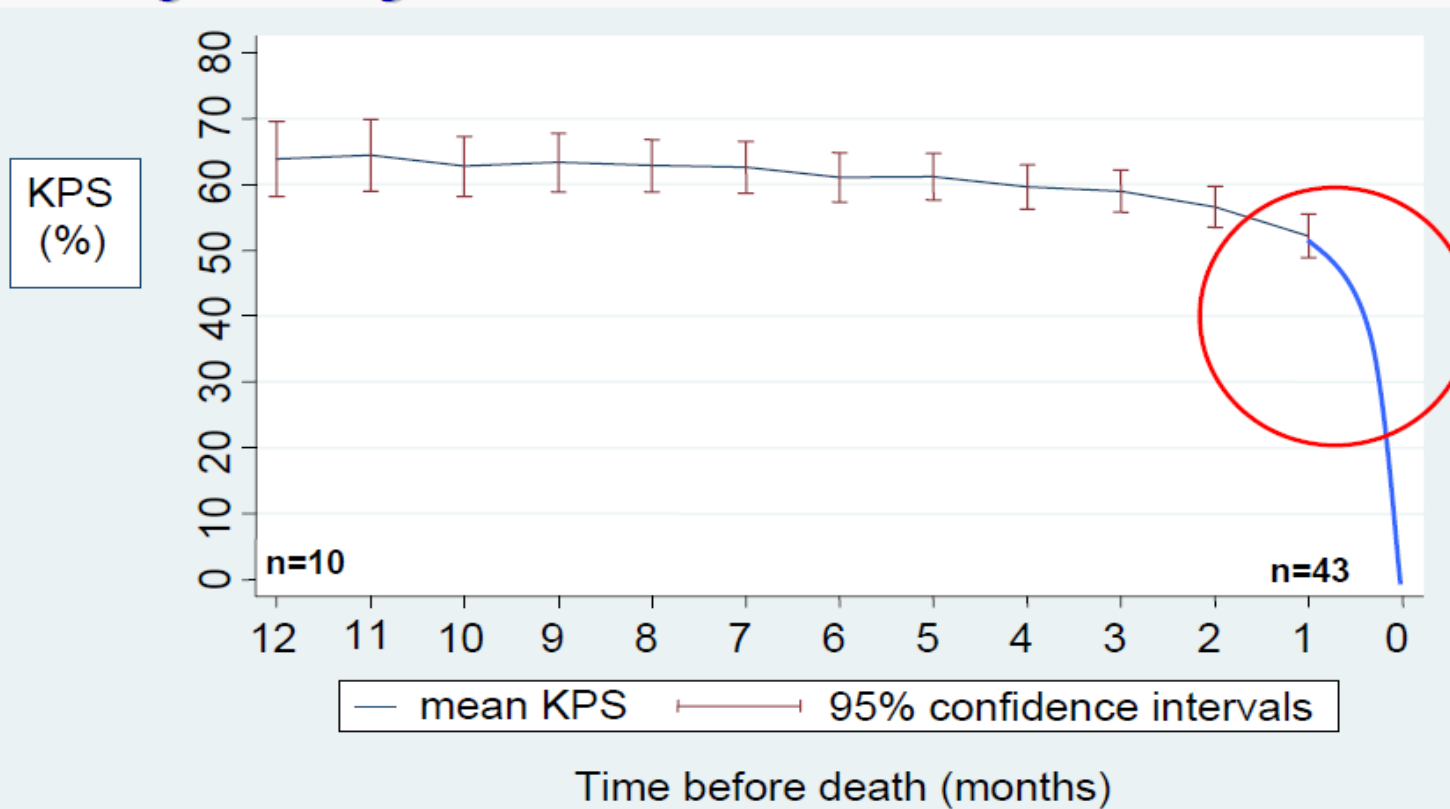
2. Withdrawal from dialysis

3. Death on a conservative, non-dialysis pathway

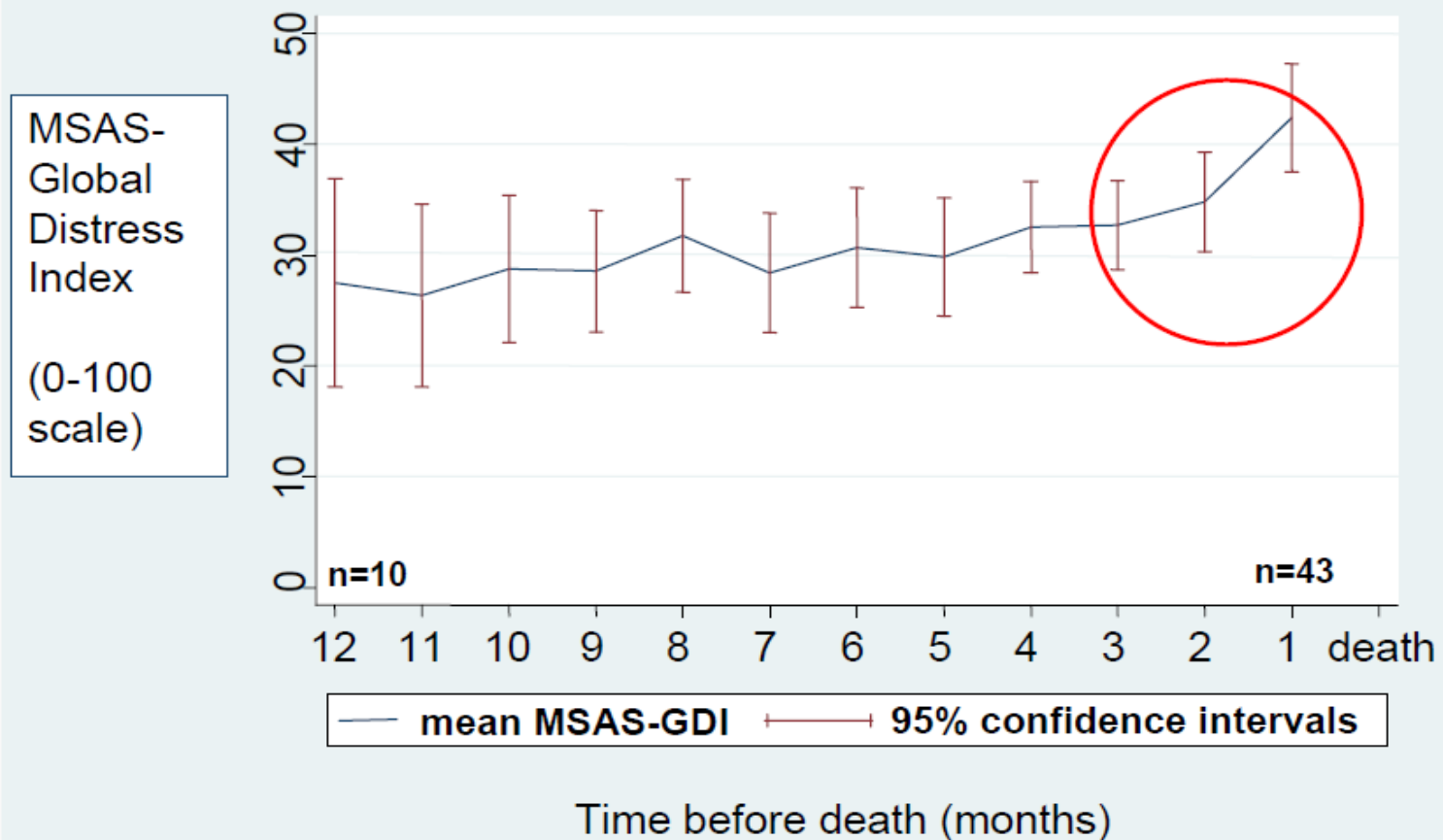
Longitudinal study of conservative stage 5 CKD

- **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)**

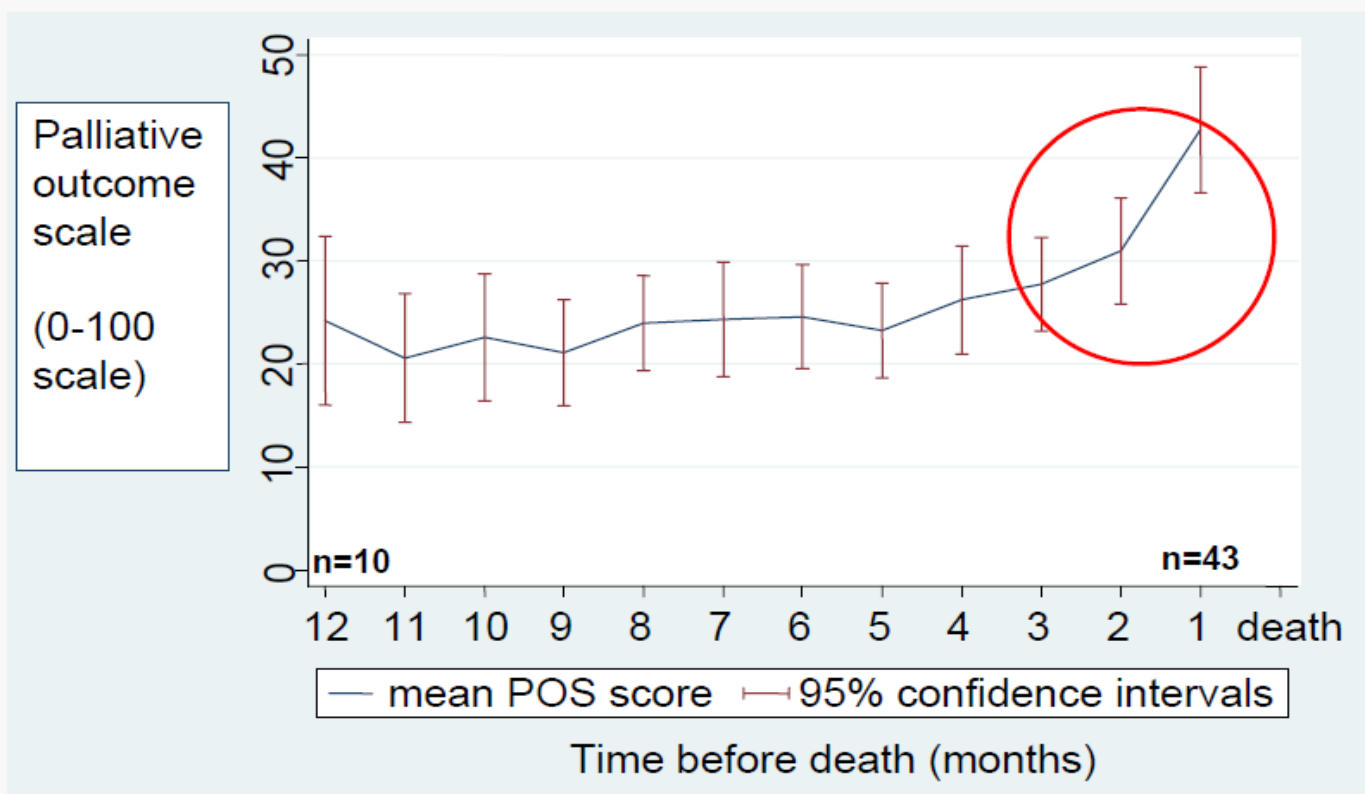
Trajectory of functional status:



Trajectory of symptom distress:



Trajectory of palliative needs:



Care of the dying patient with ESKD

“I thought there was nothing more
I could offer.”

Nephrologist

What are the important things now
to think about ?

- Location of care
- Anticipate and manage uraemic symptoms
- Anticipate and manage the general symptoms of dying
- Meticulous communication
- Support to patient, family and colleagues

Location of care

Privacy for the family

Nursing care

Medical care

Spiritual care

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.

HOME

It is their home

HOME

- Burden of physical care falls to a few.
- Exhaustion- physical and emotional.
- Need to have all supports mobilized- OT assessment; hospital bed; commode chair; shower chair ; rails.
- Community Palliative Care – vital.

1. Anticipate and manage the general symptoms of dying

2. Anticipate and manage uraemic symptoms

The Terminal phase

The stage in the disease where death is imminent.



The Terminal Phase

- Intimidating
- Confronting
- Fearful

“When I look back on it, Dad had a good death-- he was comfortable to the last...we were all there...in some ways it brought us all a lot closer as a family...Mum misses him but she was glad he didn't linger on in the weak state he was in...in many ways it was lot more peaceful than I thought it ever would be.”

Prior to the Terminal Phase

- Fears - mode of death (pain; “choking”, “drowning”)
- Explanation of what will happen, what to expect
- NFR orders

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

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

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

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.

- 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.

- What frightens you most about dying ?
- What would you most want in the terminal phase ?

FEARS :

- what will death be like ?
- fear of the after-life
- leaving family; friends
- unfinished business
- fear of particular symptoms being uncontrolled

NEEDS :

- Relief of distressing symptoms
- Security of a caring environment
- Assurance that they/their family will not be abandoned

Prior to the Terminal Phase

UNFINISHED BUSINESS :

- Unresolved conflicts
- Difficult family relationships
- Business worries
- Unfinished spiritual issues
- Legal issues – a will

Procrastination about these issues earlier in the illness may leave these issues unresolved, or, worse they are rushed in the pre-terminal or terminal phase.

“I’m sorry there is nothing
more we can do”

The Terminal Phase

FOR THE PATIENT :

1. Comfortable bed, pressure mattress.

2. Cease unnecessary medications.

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

Anti-anginals

Diuretics

3. Ceasing unnecessary observations

4. Cease unnecessary investigations

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

Anticipate and manage the general
symptoms of dying

The Terminal Phase

6. Pain – use sci opioids (avoid morphine)

Look carefully for signs of discomfort on moving and turning.

7. Agitation/restlessness – “Terminal agitation” –

sci Midazolam, intermittently or in a Syringe driver.

8. Terminal secretions – more distressing to the relatives than the patient.

Buscopan

Glycopyronium

Anticipate and manage uraemic symptoms

9. Delirium – may worsen terminal agitation

- Haloperidol
- Midazolom

10. Uraemic jerks –

Clonazepam drops sublingually or
Midazolam

11. Nausea

Metoclopramide

Haloperidol

Cyclizine

12. Pruritus

- Orals initially
- Midazolam sci

13. Mouth care –

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

14. Indwelling Catheter

Terminal Phase

FOR THE FAMILY:

Ensure there is an open
comforting environment for the
family.

PHYSICAL ENVIRONMENT :

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

Terminal Phase

EMOTIONAL SUPPORT

1. Meticulous communication

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.”

EMOTIONAL SUPPORT

3. Emotional /spiritual counseling

4. Religion –
Monk/Priest/Minister/Imam/Rabbi

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.

Communication

The importance of good communication throughout cannot be overestimated.

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

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

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.

DEATH

Importance for time to be alone with
the loved one.

BEREAVEMENT

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

Withdrawal from dialysis

Withdrawal from dialysis
may come for many reasons.

1. It is not possible to continue dialysis

Repeated hypotension on dialysis

Vascular Access issues

2. Patient is consistently exhausted with the process of dialysis.

Dialysis patients should be told that if they become consistently exhausted with the process of dialysis that they should speak to their Nephrologist about ceasing.

If the issue is symptoms then those symptoms should be addressed urgently.

3. Patient is struggling with other illnesses

- 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.

J started haemodialysis at age 76 years.

3 years later he is showing signs of dementia.

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

Here a Nephrologist
may respond in various ways.

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.”

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.”

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.”

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

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

The patient may enter a forest of suffering.

Professional courage

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

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

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

Patients survive a variable time.

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

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

- 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.

Several scenarios may occur.

Scenario 1

The major sentinel event occurs ...

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

Scenario 2

The major sentinel event occurs...

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

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

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

an Advance Care Plan

Recommended literature

Chambers EJ, Germain M, Brown E (eds)

Supportive Care for the Renal Patient

2nd edition, 2010

Oxford University Press

Brown E, Murtagh F, Murphy E.(eds)
*Kidney Disease – From Advanced
Disease to Bereavement. 2nd ed, 2012.*
Oxford Handbooks.

Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison¹, Adeera Levin², Alvin H. Moss³, Vivekanand Jha^{4,5}, Edwina A. Brown⁶, Frank Brennan⁷, Fliss E.M. Murtagh⁸, Saraladevi Naicker⁹, Michael J. Germain¹⁰, Donal J. O'Donoghue¹¹, Rachael L. Morton^{12,13} and Gregorio T. Obrador¹⁴

Oxford Medicine Online



Oxford Textbook of Palliative Medicine (5 ed.)

Edited by Nathan Cherny, Marie Fallon, Stein Kaasa, Russell K. Portenoy, and David C. Currow

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End-stage kidney disease

Chapter: End-stage kidney disease

Author(s): Fliss E. M. Murtagh

DOI: 10.1093/med/9780199656097.003.0156

Review

Renal supportive and palliative care: position statement

SU CRAIL, ROB WALKER and MARK BROWN FOR THE RENAL SUPPORTIVE CARE WORKING GROUP*

Reviews

ANZSN Renal Supportive Care Guidelines 2013**THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS**

Mark A Brown¹ and Susan M Crail², ¹Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, and ²Central and North Adelaide Renal and Transplantation Service, Adelaide, South Australia, Australia

2 For dialysis or transplantation.

3 *Indeterminate* – that group for whom the treating nephrologist and the patient are unable to come to a clear decision. For people in this group, seeking a second opinion and ideally, discussing the case at a multidisciplinary team meeting (similar to those discussions surrounding acceptance onto the transplant waiting list) are paths to follow.

A very important principle is that these planning discussions need to take place early in the course of a patient's

Decision-making around dialysis
or a conservative pathway

Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Renal Physicians Association of the USA and the American Society of Nephrology. 2010.

Brennan F, Brown M.

The ethics of dialysis – an alliance of Nephrology, Palliative Medicine and Ethics.

Quarterly Journal of Medicine 2013; 106(5): 397-400.

Advance Care Planning

- Stallworthy E. In : ANZSN Australasian Renal Supportive Care Position Paper and Guidelines. *Nephrology* 2013;18: 401-454.
- Luckett T et al. Advance Care Planning for Adults with CKD : A Systematic Review. *Am J Kid Dis* 2014 ; 63(5): 761-770.
- Holley J, Davison S. Advance Care Planning in CKD (Editorial) *Am J Kid Dis* 2014 ; 63(5): 739-740.

Pain

Davison S et al.

Pain in Chronic Kidney Disease : A
Scoping Review.

Seminars in Dialysis 2014; 27(2): 188-204.

Koncicki H et al.

An approach to pain management in End Stage Renal Disease – Considerations for General Management.

Seminars in Dialysis. April 11 2015

Uraemic Pruritus

Combs S et al.

Pruritus in Kidney Disease

Seminars in Nephrology 2015; 35(4): 383-391.

Depression

Depression and CKD : A review for clinicians

Bautovitch A et al.

ANZ J Psychiatry 2014; 48(6): 530-541.

End of life care pathway for patients with ESKD

Urban K. In : ANZSN Australasian Renal Supportive Care Position Paper and Guidelines. *Nephrology* 2013

St George Hospital Renal Department Website – Palliative Care

Commonly used Palliative Care medications in the context of CKD

St George Hospital Renal Department Website – Palliative
Care

- *The Renal Drug Handbook* (4th edition) 2014
- *The Palliative Care Formulary* (5th edition) 2014