Renal Supportive Care – An Introduction

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Department of Nephrology
St George Hospital., Sydney, Australia

Renal Supportive Care Master Class
Oxford, UK.
November 1 2019

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Overview

1. What possible role does Palliative Care have in Nephrology ?

The interface of the two disciplines.

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2. Decision making around dialysis
including the possible withholding and withdrawing from dialysis.

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3. The conservative, non –dialytic management of ESKD.

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4. The international perspective
including the New South Wales experience.

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1. **What possible role does Palliative Care have in Nephrology ?**

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What is Palliative Care ?

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WHO definition

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.

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A. Epidemiology

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Beginnings to the present

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In developed nations the mean age of patients commencing RRT

is 60 - 65 years.

In the UK – 63.7 years.

UK Renal Registry Report 2019.

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

UK Renal Registry Report 2019.

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

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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.

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> 50 % in Singapore, Malaysia, New Zealand

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

UK – 29 % (2017) UK Renal Registry Report 2019

Does everyone who has ESKD
start dialysis ?

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In Australia, for every one patient with ESKD
receiving Renal Replacement Therapy (RRT)
there is another who does not receive RRT

Australian Institute of Health and Welfare Research, 2011

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Globally

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Nation A

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

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Nation B

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

  simply reserved for those that can afford dialysis

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Nation C

- Poor resources
- Dialysis is not available

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Throughout the world, therefore, many patients with ESKD embark on a conservative, non-dialysis pathway not by choice…

but simply because dialysis/transplant is not available or affordable.

This raises the question
of the level of care
of those on dialysis
and the many who never receive dialysis.

B. 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)

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

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Annual mortality UK – for 75-84 y.o. – 23 %
- for 85 years plus – 35 %

UK Renal Registry Report 2019

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C. Symptomatology

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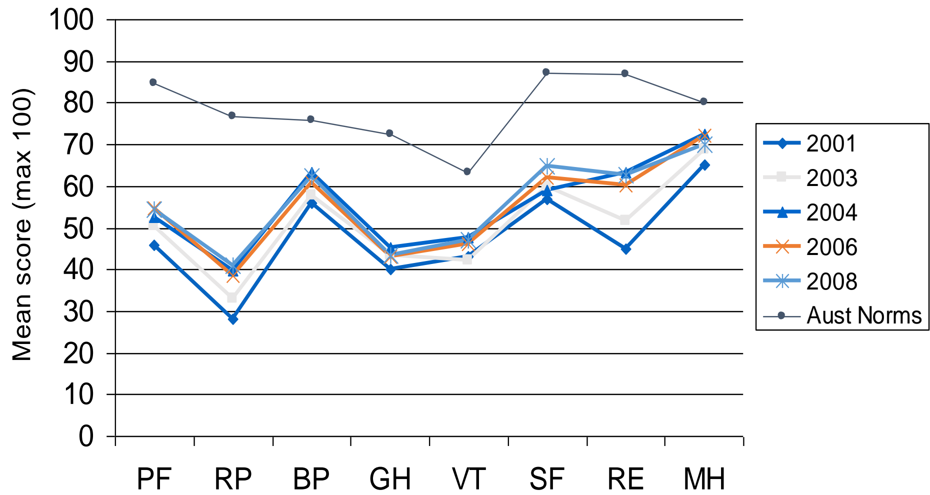
"Patients with CKD, particularly those with ESRD are among the most symptomatic of any chronic disease group."

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

D. Quality of life

QOL - St George dialysis (SF-36 Scores)



E. The "quality" of dying

The circumstances in which patients with ESRD die varies considerably.

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If it is an expected death (eg. after the cessation of dialysis or if on a non-dialysis pathway) the management of the dying phase is crucial

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

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The interface of Nephrology and Palliative Care

1. Epidemiology
2. Mortality
3. Morbidity
4. QOL
5. “Quality of dying”

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Decision making around dialysis

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Once ESRD is diagnosed it is important examine the various options.

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RRT Conservative

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One could start with the assumption that for all patients,
in all circumstances,
dialysis is the preferred option.

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Is there a cohort of patients with ESKD
where it may be more appropriate to recommend a
conservative, non-dialysis pathway
over dialysis ?

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Factors to consider:

1. Survivorship
2. QOL
3. Hospitalisations
4. Effect on carers

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Factors to consider:

1. **Survivorship**
2. QOL
3. Hospitalisations
4. Effect on carers

48

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

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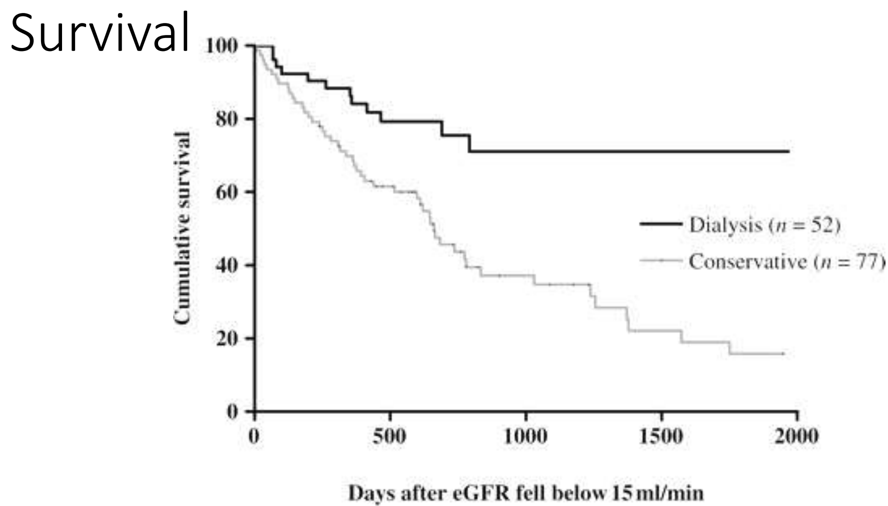
Survival



Murtagh et al. NDT. 2007;22:1955-62

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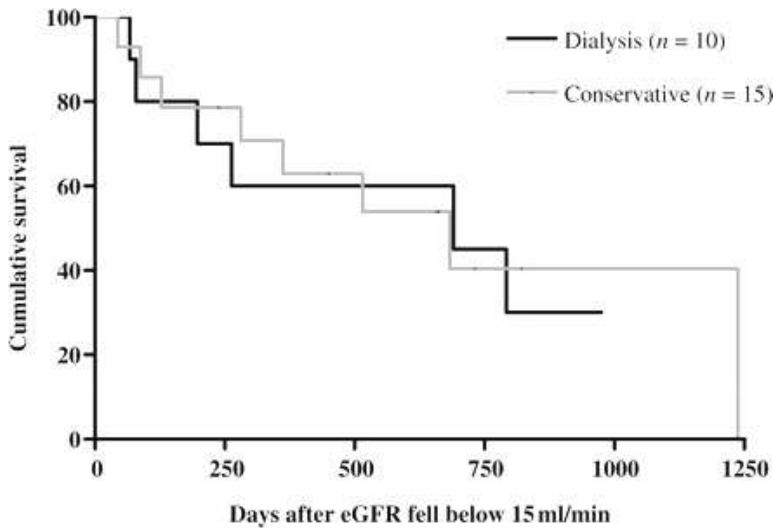
Survival benefit lost if Co-morbidities include IHD



Murtagh et al. NDT. 2007;22:1955-62

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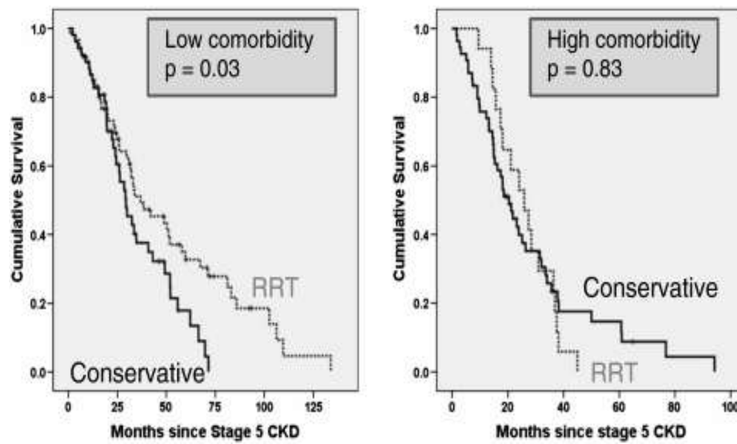
RRT v Conservative

Chandra et al NDT Nov 2010



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Carson et al CJASN 2009 went one step further…

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

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

Carson et al CJASN 2009

54

Dialysis in Frail Elders — A Role for Palliative Care

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

Volume 361:1597-1598 October 15, 2009

55

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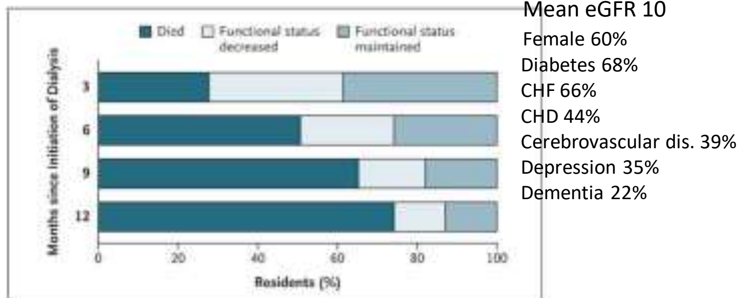
Change in Functional Status after Initiation of Dialysis

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

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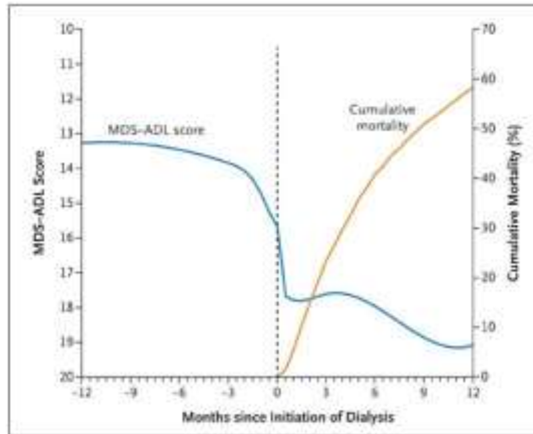
Smoothed Trajectory of Functional Status before and after the Initiation of Dialysis and Cumulative Mortality Rate

[Nursing home residents mean age 73]



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

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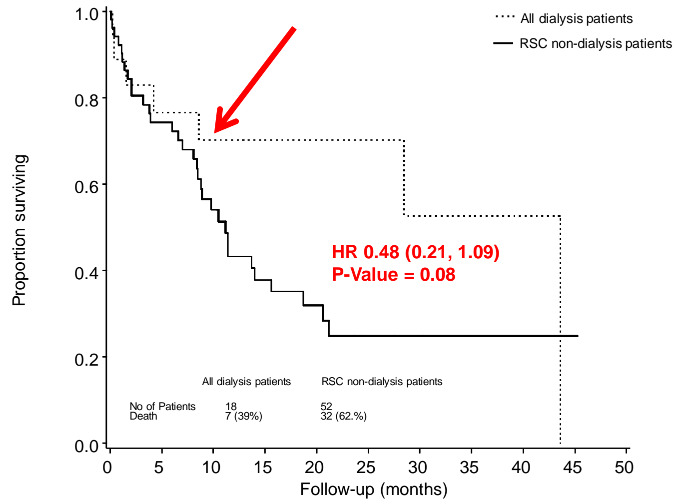
CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life

Mark A. Brown,*† Gemma K. Collett,* Elizabeth A. Josland,* Celine Foote,† Qiang Li,† and Frank P. Brennan*

CJASN 2015; 10 (2) : 260-268

58

No Survival advantage with dialysis if:
age >75 and 2 or more co-morbidities (one being CCF or IHD)



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In patients over 75 years with 2 or more co-morbidities (one of which was IHD or CCF) there was no survival advantage with dialysis compared to those who did not commence dialysis.

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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*

The Netherlands. CJASN. April. 2016

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Survival advantage lost
if ≥ 80 years old.

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Hospitalisations

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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

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Impact on carers

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Median 56-70 hours of care per week.

Belasco et al *AJKD* 2006

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All aspects of 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

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

Renal Physicians Association of the USA 2010.

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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.

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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)

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

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3. It is reasonable to consider forgoing dialysis

in those patients aged >75 with stage 5 CKD who meet 2 or more of the following statistically significant very poor prognosis criteria:

1. Clinician's response of "no, I would not be surprised" to the surprise question ("Would I be surprised if this patient died in the next year?")
2. High co-morbidity score
3. Significantly impaired functional status
4. Severe malnutrition

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The conservative, non –dialytic management of ESKD.

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1. This may be decided in consultation with a Nephrologist.

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2. The patient cannot access
or afford dialysis.

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

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What level of care occurs for this group ?

Nephrologist A

"I am sorry…
- I cannot offer dialysis to you. *or*
- That you cannot afford dialysis.

So I cannot help you…."

Nephrologist B

"Even though you are not starting dialysis, you still have kidney disease.

As a Nephrologist, I still have much to offer you.

Keep coming to see me."

81

Even though the patient may not be commencing or continuing dialysis, the Nephrologist has a great deal to offer.

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Renal medicine

- Preserving residual renal function
- Blood pressure control
- Calcium/phosphate control
- Anaemia
- Fluid balance

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So what does the conservative, non-dialysis care of a patient with ESKD look like ?

84

The care should be the best of the two disciplines

Renal Medicine	Palliative approach
Preserving residual renal function	
Blood Pressure	Symptom management
Calcium/Phosphate	Advance Care Planning
Anaemia	Psychosocial support
Fluid balance	Care of the dying

85

CKD conservative management

Not abandonment

86

CKD conservative management

Not simply transfer to Palliative Care

87

Challenge is
to ensure that this pathway of management is
thorough, systematic
and evidenced-based.

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What do we know about the
conservatively managed group of patients ?

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A. Survivorship.

B. Symptoms

C. Needs

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Survivorship

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

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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

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

94

B. Symptoms

95

A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis = NFD 1

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

The symptoms of patients with CKD stage 5 managed without dialysis. = NFD 2

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

96

SYMPTOM PREVALENCE

	NFD1	NFD2
FATIGUE/TIREDNESS	75%	88
PRURITUS	74%	69
CONSTIPATION		43
ANOREXIA	47%	62
PAIN	53%	45
SLEEP DISTURBANCE	42%	57
ANXIETY		43
DYSPNEA	61%	60
NAUSEA		
RESTLESS LEGS	48 %	
DEPRESSION		52

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C. Needs

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Over time, what happens to patients
on a conservative, non-dialysis pathway ?

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

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

Murtagh FE et al.

100

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)

www.kcl.ac.uk/palliative

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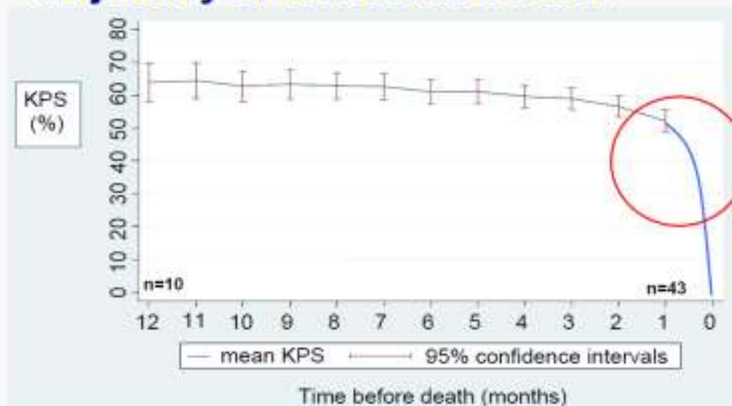

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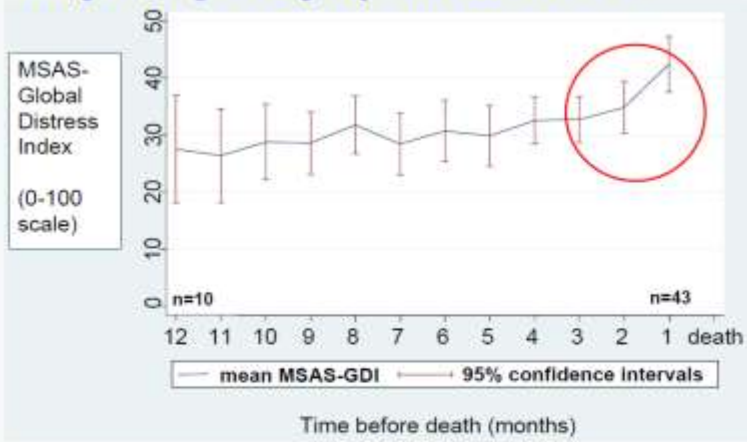

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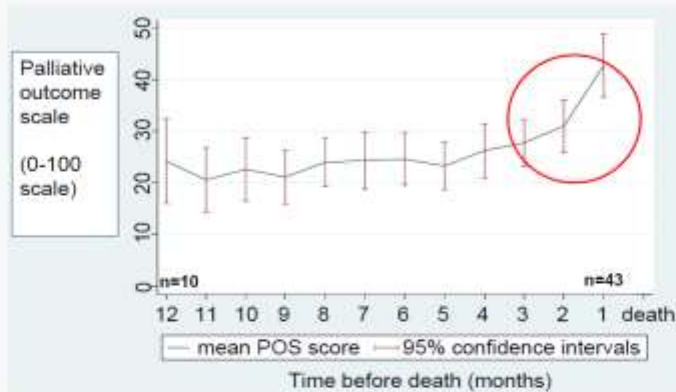

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What is happening internationally
in Renal Supportive Care ?

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http://www.kidney-international.org meeting report
© 2015 International Society of Nephrology

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

Sara N. Davison[1], Adeera Levin[2], Alvin H. Moss[3], Vivekanand Jha[4,5], Edwina A. Brown[6], Frank Brennan[7], Fliss E.M. Murtagh[8], Saraladevi Naicker[9], Michael J. Germain[10], Donal J. O'Donoghue[11], Rachael L. Morton[12,13] and Gregorio T. Obrador[14]

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In 2018
The International Society of Nephrology
hosted a summit on integrated kidney care

This endorsed the role of Renal Supportive Care.

Harris D et al. *Kidney Int* 2019; 95; S1-S33.

108

There are several national statements.

109

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

Renal Physicians Association of the USA 2010.

110

NEPHROLOGY

Nephrology 18 (2013) 393–400

Review

Renal supportive and palliative care: position statement

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

NEPHROLOGY

Nephrology 18 (2013) 401–454

Reviews

ANZSN Renal Supportive Care Guidelines 2013

THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS

Mark A Brown[1] and Susan M Crail[2], [1]Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, and [2]Central 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 discus-

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National RSC Position Statements
have been published or are in preparation in :

- India
- Czech Republic
- Thailand
- South Africa

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Annual Renal Supportive Care Symposia

London

St George and Nepean Hospitals, Sydney

Royal Brisbane Hospital

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Master Classes/ workshops on Renal Supportive Care

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- Sri Lanka (2015)
- Ireland (2016)
- Malaysia (2017)
- Thailand (2017, 2018, 2019)
- India (2018) – Zoom lecture series
- India (2019)
- South Africa (2019)
- Australia (2015, 2019)
- United Kingdom – Oxford (2019)

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The New South Wales experience

116

Commenced in the Renal Department
St George Hospital, Sydney.

117

It started with a conversation

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It started with a conversation
about the needs of patients

119

Much of that conversation consisted of a series of meetings between
Palliative Care team and the Renal Nurses.

There was a clear recognition that it was the Renal/dialysis nurses
who were witnessing the struggles of dialysis patients
on a daily basis.

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There was also an early recognition that:

with so few Palliative Care health professionals, already engaged with other diseases,

it was vital to enhance the skills of Nephrologists, Renal trainees, Renal Nurses and Allied Health in this area.

121

At the beginning there was no funding.

122

"Start will good will."

Professor Mark Brown, Nephrologist, St George Hospital, Sydney.

123

A Renal Supportive Care Service
within the Department of Nephrology

124

RSC Clinic weekly :

65 % conservative patients
35 % dialysis patients

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RSC Clinic weekly :

65 % conservative patients
35 % dialysis patients – symptomatic, struggling

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Lines of referral

Open

Triaged by Renal Supportive Care Nurse

127

Symptom census of all dialysis patients every 6 months.

128

Symptom census of all dialysis patients every 6 months.

If report any moderate to overwhelming symptoms – automatic referral the RSC Clinic.

129

Each patient, at each presentation, completes the IPOS-Renal in the waiting room.

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IPOS-Renal Patient Version

POS
www.pos-pal.org

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

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	☐	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐	☐
Weakness or lack of energy	☐	☐	☐	☐	☐
Nausea (feeling like you are going to be sick)	☐	☐	☐	☐	☐
Vomiting (being sick)	☐	☐	☐	☐	☐
Poor appetite	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐
Sore or dry mouth	☐	☐	☐	☐	☐
Drowsiness	☐	☐	☐	☐	☐
Poor mobility	☐	☐	☐	☐	☐
Itching	☐	☐	☐	☐	☐
Difficulty Sleeping	☐	☐	☐	☐	☐
Restless legs or difficulty keeping legs still	☐	☐	☐	☐	☐
Changes in skin	☐	☐	☐	☐	☐
Diarrhoea	☐	☐	☐	☐	☐

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?	☐	☐	☐	☐	☐
Q4. Have any of your family or friends been anxious or worried about you?	☐	☐	☐	☐	☐
Q5. Have you been feeling depressed?	☐	☐	☐	☐	☐

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	☐	☐	☐	☐	☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	☐	☐	☐	☐	☐
Q8. Have you had as much information as you wanted?	☐	☐	☐	☐	☐

	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)	☐	☐	☐	☐	☐

	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	☐	☐	☐

	On my own	With help from a friend or relative	With help from a member of staff
Q11. How did you complete this questionnaire?	☐	☐	☐

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

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Personnel:

Palliative Care Physician
Nephrology Trainee
Renal Supportive Care Nurse
Renal Social Worker
Renal Dietician

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In other clinics in Australia
the Nephrologist has led the clinic

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The crucial role of a Renal Supportive Care Nurse

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To co-ordinate the Service
and the other members of the team.

To ensure that patients needs are being addressed
and followed up.

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From the beginning
the attendance of the Nephrology Trainee
at the RSC Clinic has been crucial.

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The model in Christchurch, New Zealand

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Clinic (non-funded)

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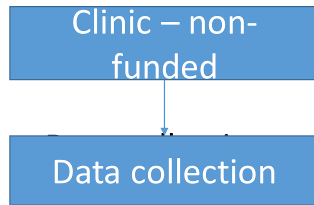

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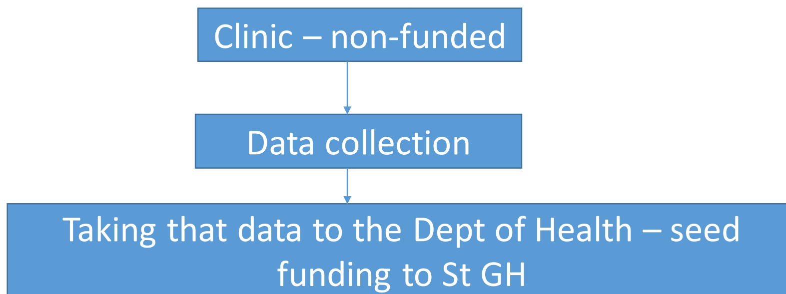

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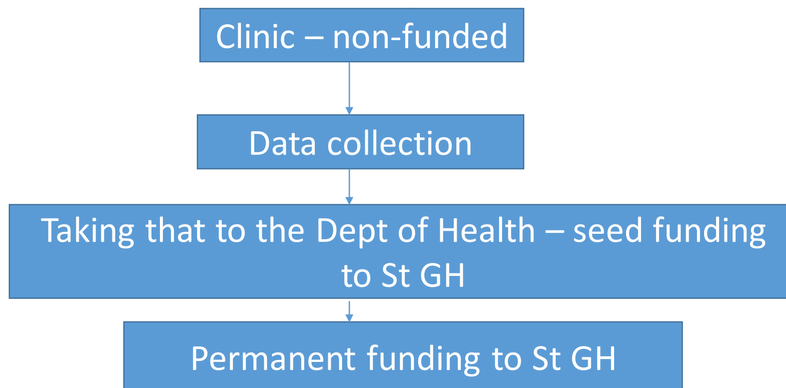

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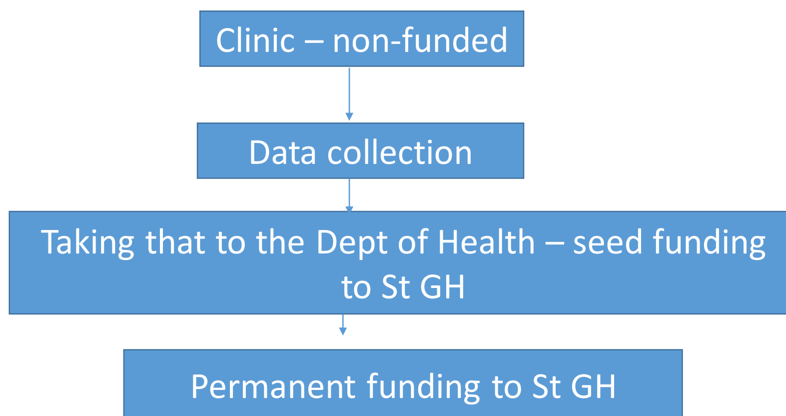

Annual Symposia, publications, lectures,
National Guidelines, JMO/Registrar/Nursing teaching.
Observerships by national and overseas visitors.

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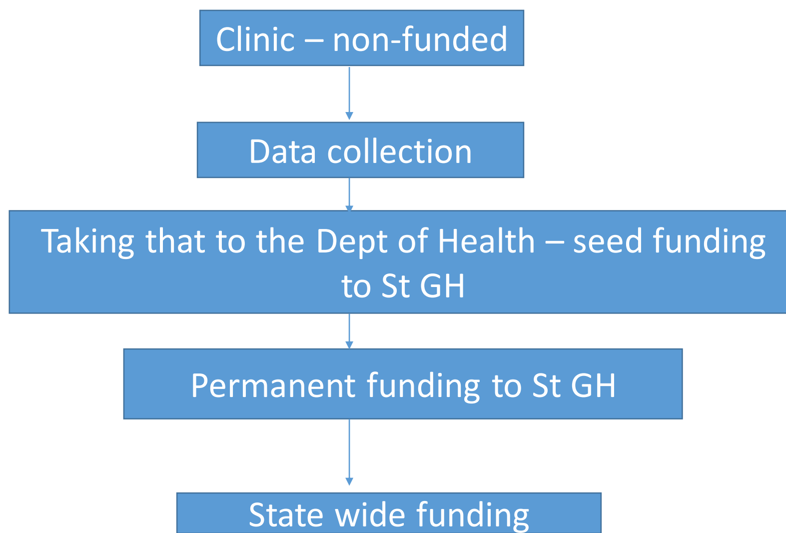

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In addition to the Clinic
the RSC Service includes…

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- In-patient referrals
- Community visits
- Education and research

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6 x tutorials on RSC for junior doctors working in Renal Medicine.

Department of Nephrology, St George Hospital, Sydney.

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Annual Renal Memorial Service

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Conclusion

The role of Palliative Care/Supportive
Care in ESKD

A mutual acknowledgement of need.

148

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Conclusion

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

Much work needs to be done at all levels.

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