THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS

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- Nephrologists seek to provide dialysis to those who will benefit most while being honest and direct with those who are unlikely to benefit or even be harmed by dialysis; these can be difficult decisions.
- A ‘conservative’ or ‘not for dialysis’ pathway is an important option for the management of end-stage kidney disease (ESKD) patients who are elderly, have significant comorbidity, poor functional status, malnutrition or who reside in a nursing home.
- Such a pathway is best underpinned by a specific renal supportive care programme in each unit.
- Nephrologists need to lead realistic discussions about likely survival with patients and their families before dialysis is instituted.
- Key ethics principles are a good aid in this decision-making process.
- A ‘non-dialysis’ renal supportive care programme is a very positive way of offering holistic care for patients and their families; many of these patients live much longer without dialysis than might have been expected.

Perhaps the most difficult decision facing nephrologists today is that of ‘selecting’ which patients will benefit from dialysis in an overall person-centred sense, not just in terms of days survived or achievement of target haemoglobin, Phosphate, Kt/V or other outcomes. The overall aim is to help and direct patients and their families so as to encourage those who will benefit most from dialysis to have this while being honest and direct with those who are unlikely to benefit or even be harmed by dialysis. Consequently it is imperative that we have mechanisms in place that support those who do not receive dialysis in such a way that they have good symptom control and quality of life (QOL).

While the discussions below apply to every potential dialysis patient regardless of age, in practice most ‘younger’ patients (below 70) are likely to be offered dialysis; these considerations below become far more relevant for discussions with patients who are over 70 years old with stage 4 or 5 end-stage kidney disease (ESKD). We are therefore looking at three potential pathways for patients with ESKD:

1 Not for dialysis or transplantation – a clear decision based on medical and ethical grounds incorporating the patient’s wishes.

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 management, probably when estimated Glomerular Filtration Rate (eGFR) reaches 25 mL/min.

There are some key principles that can help nephrologists, patients and their families make these decisions:

1 Nephrologists need to lead these discussions – these are very difficult discussions but it is imperative that as nephrologists we do not shy away from them as this is to the ultimate detriment of the patient and their family. In some centres it may be that nephrologists do not see the same patients regularly and the temptation here will be either to use dialysis as the default choice for all patients or else to leave these discussions to other medical or nursing staff. It is inappropriate for these discussions to be delegated to more junior medical staff but advanced trainees and Junior Medical Officers (JMOs) should be present as part of their training. Initial discussions are generally best if done with the nephrologist and his/her medical team, and then followed by more detailed discussions with nursing staff and allied health staff. Ideally a renal supportive care (RSC) programme team will help facilitate these ongoing discussions with a patient and their family when a conservative not-for-dialysis pathway is chosen and a pre-dialysis team will assist those for whom dialysis is considered the correct management pathway.

Many nephrologists have already made it part of their usual practice to offer a ‘non-dialysis’ pathway to selected patients but many are also understandably troubled when making such decisions. This issue has become more prominent because of the increasing number of aged patients with comorbidities, frailty, or poor functional status who present with end stage kidney disease, for whom decisions need be made as to the appropriateness of dialysis.

2 Nephrologists need to have realistic discussions about likely patient survival on dialysis – data are available from Australian and New Zealand Dialysis and Transplant Association (ANZDATA) to guide this. We need to be aware that these discussions are likely to be aimed at frail, ‘marginal’ patients of any age although most of the available data deal specifically with those over the age of 75 years:

a. Current data show that patients starting dialysis in the 75–84 years age group, presumably already selected to some extent by their nephrologists as suitable...
candidates, have a 20% death rate in the first year on dialysis and only a 17–25%¹ chance of living 5 years. Survival is much worse for those aged 85 or older at commencement.

b. Put in context, survival on dialysis for an average 60-year-old patient is worse than for most cancers. Data from the Cancer Council of Australia (http://www.cancer.org.au) show that the overall 5-year survival rates for prostate cancer are 92%, breast cancer 89%, renal cancer 72%, bowel cancer 66%, ovarian cancer 43% and lung cancer less than 14%. Data from ANZDATA (http://www.anzdata.org.au) show that 5-year survival on dialysis in Australia is 60% for patients aged 45–64, 40% for those aged 65–74 and 25% for those aged 75–84, with slightly lower survival rates for the New Zealand population. Overall heart failure survival is similar or better than the above dialysis survival rates (5-year age-adjusted heart failure survival, 52% in 1996–2000, JAMA 2004; 292(3):344).

c. Withdrawal from dialysis due to psychosocial reasons is now almost the highest cause of death in dialysis patients.

d. Survival of elderly patients with comorbidities may be no better with dialysis than without. Chandna et al.² showed that in patients >75 years of age with high comorbidity scores, survival did not appear to be improved by dialysis and in fact, some lived longer without dialysis compared with those who chose to undergo dialysis.

e. Survival for non-dialysis patients is less well documented; it is almost certainly worse so the dialysis decision comes down to balancing between the burden of dialysis and days survived.

f. An estimation of survival time on dialysis may aid patients in coming to a decision. Comparing survival expectations to cancer survival rates may help some to understand the limitations of dialysis.

3 Nephrologists need to have realistic discussions about QOL on dialysis – the fact is that all aspects of QOL are worse for elderly dialysis patients than the general Australian population; for some patients this is an acceptable ‘trade-off’ but for others this is not acceptable. Of course, perceived QOL is a very individual issue and this is where realistic discussions need to take place. In this regard Morton et al.³ have found in an Australian population with ESKD that patients are willing to forgo 7 months of life in order to reduce the number of visits to hospital each week for dialysis, and 15 months to minimize restrictions on their ability to travel. The burden on carers is similar to that of caring for those with dementia or Parkinson’s disease and it increases with home dialysis and patient comorbidities.

4 Nephrologists can be assisted by applying four key ethical principles to this decision-making process: ⁴

a. Autonomy

Is the patient, having been properly informed of the pros and cons of dialysis, capable of making a decision whether or not to have dialysis?

b. Non-maleficence

We have an obligation to do no harm to our patients; suffering is harm and we need to judge carefully whether dialysis will increase suffering. Swidler⁵ states that ‘although dialysis is life-sustaining therapy and extends life, it may also create, increase or prolong suffering while not restoring or maintaining well-being, function or cognition’ . . . and ‘to address suffering it must first be realised’. The burden of suffering may not be realized by a consultant who sees the patient infrequently but will be borne greatly by dialysis nurses and registrars. This is an often neglected ethical issue.

c. Beneficence

We are obliged to provide our patients with the greatest benefit; to this end we should do our utmost to select patients most likely to benefit from dialysis, not just in terms of prolongation of life but in maintenance of worthwhile QOL.

d. Justice

We are obliged to provide our patients equal opportunity and allocation of available resources; in general terms we are fortunate in Australia and New Zealand that this principle rarely comes into play when making decisions around dialysis.

5 There are predictive models available (these are discussed in more detail in the section by Katz and Robbins on ‘Predictive modelling, risk calculators and the non-dialysis pathway’) that assist nephrologists in making these decisions. Broadly speaking we need to consider:

a. The ‘surprise’ question: would you (nephrologist) be surprised if your patient died in the next 12 months?


c. Age.

d. Comorbidities.

e. Functional status.

f. Is the patient in a nursing home? – Data for nursing home patients receiving dialysis show very poor outcomes with only 25% alive after 12 months and only 15% retaining their functional status.⁶

6 Nephrologists need to ensure patient expectations about dialysis are realistic – although outcomes in the elderly are often poor, Davison found that only 18% felt their condition would deteriorate in the next year.⁷

7 Nephrologists should guide the decision – not just leave the patient and the family with a host of information and ask for a decision; many elderly patients are relieved to learn that dialysis is not compulsory. Davison and Simpson⁸ found that 60% regretted their decision to start dialysis and most of these started because they felt it was what their nephrologist wanted. Patients are mostly comfortable with realistic discussions but they often do not happen. They do not lose hope in life by having these discussions; in fact the opposite is true.⁸

8 If a decision is made to forgo dialysis then it is imperative that the patient and family are informed about the positive
things that can be put in place, ideally through a RSC programme that encompasses holistic and palliative care to address symptom burden and QOL, and at a later stage to facilitate ‘good death’. The principle of non-abandonment is essential to the patient’s welfare and they need to know that they will continue to receive usual nephrology care as well as RSC. In addition, patients and their families need to know that the decision to follow a ‘non-dialysis’ pathway can be re-considered at any stage. One useful approach is to begin each consultation with a statement that the patient’s current pathway is that of a supportive ‘non-dialysis’ treatment and seek clarification that he/she and the family agree that this remains the most appropriate management pathway or whether that decision requires review.

9 Patients who choose to have dialysis also deserve to have access to special management of burdensome symptoms and can be aided by treatments used for people on the RSC pathway. This may have implications for those who had been considering withdrawal from dialysis because of severity of symptoms and may potentially change their decision with improved management.

In summary, nephrologists’ thinking about elderly patients with ESKD needs to shift from traditional markers of medical ‘success’ to focus on the patients’ symptoms and function as much or more than survival. This will help make an appropriate decision about suitability for dialysis. We believe that in making the decision to embark upon or forgo dialysis, we should consider all the above principles and enhance ESKD patient & family education to ensure that the option of non-dialysis conservative RSC is at least an equal offer to dialysis. This is best done with a formal RSC programme in place in each unit. Importantly all elderly patients with ESKD who do not receive dialysis need to not feel abandoned and know that all ongoing ESKD treatment will continue with their nephrologist.

Finally, we already have some guidelines that discuss when it is OK to forgo dialysis, including Caring for Australians with Renal Impairment (CARI) & Renal Physicians Association (RPA) USA guidelines, discussed in the section by Crail ‘Management guidelines for patients choosing the RSC pathway: Information and web-based treatment protocols available to all’.

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REFERENCES


PERSPECTIVE – THE ISSUES SURROUNDING END-STAGE KIDNEY DISEASE AND DIALYSIS IN THE ELDERLY AND THOSE WITH COMORBIDITIES

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- There is a disproportionate increase in the number of elderly patients, many with multiple comorbidities, commencing dialysis.
- Predictors of survival for elderly patients on dialysis include age, comorbidity score, malnutrition, poor functional status and late referral.
- Patients with high comorbidity scores may not gain a survival advantage with dialysis versus a non-dialysis pathway.
- Late referral and lack of dialysis access are independent predictors of mortality in elderly patients commencing dialysis.
- Hospital free survival may be similar in dialysis and non-dialysis treated groups.
- We have few data on those choosing not to start dialysis in terms of numbers, clinical course and survival.
- Most available data are not from an Australian or New Zealand source.
- The effects on quality of life of different management pathways on patients, carers and staff still need to be addressed.

INTRODUCTION

The number of patients with end-stage kidney disease (ESKD) is growing, with the greatest increase over the last decade among those who are elderly, dependent and with multiple comorbidities.1,2 As a consequence, the annual acceptance rate for renal replacement therapy (RRT) in Australia is rising with the highest prevalent dialysis groups being the 65–74
years age cohort (24%) and the over 75 years old age group (24%). It is also noteworthy, that in the past 5 years, the greatest percentage increase in acceptance on dialysis has been in the over 75 years old age group. Although ANZDATA (Australian and New Zealand Dialysis and Transplant Registry) provides data on the stock and flow of elderly patients on RRT, there exists no registry data of the number of elderly patients reaching chronic kidney disease (CKD) stage V who choose not to dialyse. Results from the Patient INformation about Options for Treatment (PINOT) study showed that 14% of incident stage V CKD patients chose a non-dialysis pathway but this does not account for the undefined number of people who, in consultation with their physician and family choose not to dialyse and are never referred to nephrology services in the first instance. The Australian Institute of Health and Welfare (AIHW) study suggests that for every patient (usually elderly) who dies on RRT another dies without having the desire for or access to RRT.

We have reached an important crossroad in the provision of dialysis services where technology has improved to such a degree that there exists few limitations in the ability to commence dialysis irrespective of age or comorbidities. However, in conjunction with this change in practice, there is increasing recognition among nephrologists and renal service providers that dialysing those with increasing dependence and multiple comorbidities may not improve survival and may adversely affect their quality of life. Few qualitative studies have explored the factors that elderly ESKD patients consider when making treatment decisions but some of the factors identified to date include survival, quality of life and burden of treatment.

CHARACTERISTICS OF ELDERLY PATIENTS WITH ESKD

- Elderly ESKD patients who commence dialysis in Australasia have a considerable comorbid burden (70% with cardiovascular disease, 60% coronary artery disease, 33% peripheral vascular disease, 24% cerebrovascular disease).
- Elderly ESKD patients who commence dialysis in Australasia often start without established access (46%) and one-third are referred late.
- There is little information about the characteristics of elderly ESKD patients in Australasia who are managed with non-dialysis pathways.

An ANZDATA study, which included 1781 patients aged 75 years or older who started RRT between January 2002 and December 2005 and followed them until 31 December 2007, showed that 91% of patients had at least one, and almost half had three or more comorbidities. Two-thirds of patients had coronary disease, one-third had peripheral vascular disease and one quarter had cerebrovascular disease while 70% had some form of vascular disease. An appreciable number of elderly patients (46%) commenced dialysis without permanent access and approximately one-third commenced RRT less than 3 months after nephrologist review.

Patients on non-dialysis pathways tend to be older, with more functional impairment and social isolation but these studies to date are not derived from an Australasian cohort.

SURVIVAL: DIALYSIS VERSUS A NON-DIALYSIS PATHWAY

- Elderly ESKD patients who commence dialysis have considerable mortality. An Australasian study showed 1-year survival of 77%, 2-year survival of 59% and 3-year survival of 45%.
- Survival of elderly ESKD patients on a non-dialysis pathway is difficult to estimate because of lack of data.
- Survival without dialysis may be between 9 and 22 months.

From ANZDATA and other international registry data, we have accurate information on the overall survival from the point of initiating dialysis within a given age group. It is clear that elderly patients on dialysis have a substantial decrease in actuarial survival compared with the age matched population. The survival of Australasian elderly dialysis patients was as detailed above and was markedly less than the actuarial survival of a similarly aged person not requiring dialysis as shown in Figure 1.

These findings have been echoed in publications from other large international registry databases. In a US Renal Data System (USRDS)-based study looking at outcomes of all nursing home residents in the USA following initiation of dialysis, the authors reported mortality rates of 24% in the first 3 months after dialysis initiation and 58% at 12 months.

Survival on a non-dialysis pathway is more difficult to determine as there have been few studies, each containing small numbers of patients (Fig. 2). Some studies have reported outcomes on patients of all ages while others have focused on the elderly and the studies have used different points from which to measure survival, ranging from an epidermal growth factor receptor (eGFR) of 10 or 15 or a putative dialysis date. The reported survival varies between 6 and 23 months in studies with patients of all ages and 9 and 22 months in studies in the elderly. This lack of evidence and variation in mortality makes it difficult for nephrologists to draw conclusions regarding survival on a non-dialysis pathway. Another thing to consider is that the most of these studies were conducted on the UK where practice patterns and characteristics of patients may be different from Australasia.

PREDICTORS OF SURVIVAL FOR ELDERLY PATIENTS WITH CKD STAGE V: DIALYSIS VERSUS A NON-DIALYSIS PATHWAY

- Predictors of survival for elderly patients on dialysis include age, comorbidity score, malnutrition, poor functional status and late referral.
Patients with high comorbidity scores may not gain a survival advantage with dialysis versus conservative care.

Late referral and lack of dialysis access are independent predictors of mortality.

Hospital free survival may be similar in dialysis and non-dialysis treated groups.

Several studies have also identified comorbidity score as a strong predictor of mortality. Few studies have examined factors associated with survival in patients treated on a non-dialysis pathway. One prospective observational study carried out by Wong et al. using the validated Stoke comorbidity score showed that comorbidity grading predicted survival in these patients, with percentage survival at 1 year ranging from 83% in those with a grade zero score to 56% in those with a grade 2 comorbidity score.

Studies looking to identify factors that might predict a survival benefit for dialysis versus non-dialysis care. There are however a number of well-conducted observational studies that have attempted to overcome the bias of their retrospective nature, to compare the outcome of dialysis versus non-dialysis care in this elderly cohort. Results of comparative studies suggest that survival advantage on dialysis is lost when there is a high comorbidity score, particularly coronary disease, poor functional ability and high social dependence. The largest of these studies published by Chandna et al. from the UK, studied 844 patients over an 18-year period. They found that in patients over 75 years of age with high comorbidity, RRT was not associated with a significant increase in survival compared with those who were not dialysed. Similarly in another UK study, Murtagh et al. showed that although overall survival with dialysis was superior (84% vs. 68% 1-year survival), the survival benefit was lost in those with a high comorbidity score, with cardiovascular disease being the most predictive of poor outcome. By way of comparison, the ANZDATA statistics show that a high proportion of elderly patients on dialysis in Australia have several factors predictive of a poor outcome on dialysis.

Quality of Life and Burden of Treatment in Elderly ESKD Patients

- Dialysis therapies in elderly ESKD patients are associated with decreased quality of life compared with the general population but it may be relatively preserved compared with younger dialysis patients.
- Dialysis therapies in the elderly are also associated with increased hospitalization and functional decline.
- Carers of elderly patients on dialysis show decreased quality of life and a substantial number also have signs of depression.
We have little information about quality of life or functional decline with non-dialysis pathways and little information on the impact on carers in this group.

Few studies have examined outcomes other than survival in elderly patients with ESKD. Health-related quality of life in elderly dialysis patients appears to be decreased compared with elderly persons in the general population although may be better preserved than in a younger cohort of patients where the perceived reduction in health-related quality of life associated with dialysis is greater. Many factors will impact on a patient’s quality of life and may influence their decision to dialyse or not.

An important concept is that of hospital free survival. Dialysis in elderly patients is associated with increased hospitalization with rates of hospitalization in elderly RRT patients of 20–35 days per year compared with 10–16 days per year in those on non-dialysis pathways. One UK study published by Carson et al. concluded that elderly haemodialysis patients spent almost 50% of the time they survived in hospital or attending to dialysis compared with those on non-dialysis pathways who spent just 4.3% of their days. This crucial information is frequently not imparted to patients or considered by nephrologists when discussing the option of RRT.

Evidence also exists that elderly dialysis patients have one of the highest prevalence rates for frailty of any single population and that initiation of dialysis may be associated with considerable functional decline. Jassal et al. showed that in those aged ≥80 who commenced dialysis (80% of whom were living independently at home), 30% had functional loss 6 months after dialysis initiation (required community/carer support or transfer to a nursing home). Another study by Kurella Tamura et al. showed that the majority of elderly nursing home residents have died (60%) or lost function (27%) 12 months after dialysis initiation.

The elderly can have specific medical issues and needs that are best assessed by an Aged Care Physician. This is recommended particularly when assessment of cognitive function is a part of the considerations in determining whether dialysis is appropriate or not. Finally carers of elderly dialysis patients also have impaired quality of life with all components of The Short Form (36) Health Survey (SF36) affected and 32% of carers with signs of depression in one study. We have no information on the impact of carers of elderly patients on non-dialysis pathways and further studies are required.

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**PREDICTIVE MODELLING RISK CALCULATORS AND THE NON-DIALYSIS PATHWAY**

**Jennifer Robins and Ivor Katz**, Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, Australia

**RECOMMENDATIONS**

- Documenting five key variables important in determining mortality associated with dialysis:
  1. Nephrologist response to the Surprise Question.
  2. Age.
  3. Comorbidities.
  4. Functional status.
  5. Nutritional status.
- Use of the Surprise Question in all patients: on dialysis or those patients on, or being considered for, a non-dialysis pathway.
- Use of the clinical score by Couchoud et al. (2009) for patients being considered for a non-dialysis pathway.
- Use of the modified Charlson score (MCS) and the clinical score by Cohen et al. (2010) for dialysis patients being considered for transition to a non-dialysis pathway (particularly the elderly with comorbidities).
- Consider withholding dialysis if a patient over 75 years of age has two or more of the following:
  1. Nephrologist response to the Surprise Question of ‘No, I would not be surprised if my patient died within the next 12 months’.
  2. High comorbidity score (e.g. MCS $\geq 8$).
  3. Marked functional impairment (e.g. Karnofsky performance status score $< 40$).
  4. Severe chronic malnutrition (serum albumin $< 25$ g/L using the bromcresol green method).

This guideline will review the current prediction models and survival/mortality scores available for decision-making in patients with advanced kidney disease who are being considered for a non-dialysis treatment pathway.

Risk prediction is gaining increasing attention with emerging literature suggesting improved patient outcomes through individualized risk prediction. Predictive models help inform the nephrologist and the renal palliative care specialists in their discussions with patients and families about suitability or otherwise of dialysis. Clinical decision-making in the care of end-stage kidney disease (ESKD) patients on a non-dialysis treatment pathway is currently governed by several observational trials. Despite the paucity of evidence-based medicine in this field, it is becoming evident that the survival advantages associated with renal replacement therapy in these often elderly patients with multiple comorbidities and limited functional status may be negated by loss of quality of life, further functional decline, increased complications and hospitalizations.

Here we review the pertinent predictive models and risk calculators for ESKD and highlight the advantages and disadvantages associated with each. It is important to recognize that there is currently no consensus for conducting or reporting the development and validation of multivariate prediction models. Prediction models for chronic kidney disease were often developed using inappropriate methods and were generally poorly reported. A ‘c-statistic’ is a measurement of how well the model predicts the event. A c-statistic of 0.5 = no better than chance; a c-statistic of 1.0 = perfect prediction and is acceptable if $\geq 0.7$. Models considered to be well reported include the Journal of the American Medical Association (JAMA) Tangri et al. model. The patient population in which the score was developed should be taken into account.

**WHAT PREDICTIVE MODELS ARE AVAILABLE TO ASSESS NON-DIALYSIS ESKD PATIENTS?**

Decision-making for ESKD patients are currently being guided by existing mortality prediction models developed and validated in dialysis patients.

When considering treatment choices it is important to consider the following facts. There are around 800 kidney transplant operations performed annually. As at 4 January 2012 there were 1135 people waiting for a kidney transplant in Australia, which represents approximately 11% of the people receiving dialysis. Seventy-three per cent of people on the waiting list are aged less than 60 years, and 79% are waiting for their first transplant. The average waiting time for a transplant is about 4 years, but waits of up to 7 years are not uncommon. On average one Australian dies each week while waiting for a transplant.

There are also paradoxical factors impacting on the outcome of dialysis patients such as that of high body mass index being associated with improved survival. A similar reverse epidemiology of obesity has been described in geri-
atric populations. The ‘reverse epidemiology’ of obesity or dialysis-risk-paradoxes need to be considered in the decision-making equation. Efforts to obtain a better understanding of the existence, aetiology and components of the reverse epidemiology and their role in maintenance dialysis patients remain of paramount importance for future study.

Newly emerging predictors of mortality in the non-dialysis population include a high comorbidity score,4,5,13 functional impairment1 and acute kidney injury secondary to a sentinel event or events on a background of chronic kidney disease (CKD). A predictive model that comprehensively incorporates variables relevant to the prognostic outcome of the non-dialysis population has yet to be developed. The evaluation of the needs in the Australian population in context to these scores must also be considered in the decision-making process and remains an unanswered area requiring investigation. The majority of the models below were specifically designed for the dialysis pathway population.

1. The JAMA Kidney Failure Risk Equation1

The JAMA Kidney Failure Risk Equation (KFRE) is a predictive model, which uses demographic information and routine laboratory markers of CKD to predict which patients with CKD stages 3 to 5 will progress to the need for dialysis.1 Risk is given as a 5-year percentage risk of progression to ESKD.

<table>
<thead>
<tr>
<th>Population validated for:</th>
<th>CKD stages 3 to 5 (c-statistic, 0.917)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(95% confidence interval, 0.901–0.933)</td>
</tr>
</tbody>
</table>

**Advantages:**
- Uses routine demographic and laboratory markers of CKD (Table 1)
- The first predictive model to accurately predict CKD progression to ESKD

**Disadvantages:**
- Awaiting validation in the Australian CKD population
- Requires a risk calculator available as:
  - an Office Excel spreadsheet (http://jama.ama-assn.org.wwwwproxy0.library.unsw.edu.au/content/305/15/1553.full.pdf+html)
  - smartphone app (http://www.qxmd.com/Kidney-Failure-Risk-Equation)

### Table 1 Variables required for the Kidney Failure Risk Equation (KFRE)

<table>
<thead>
<tr>
<th>Variables required (KFRE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Estimated glomerular filtration rate</td>
</tr>
<tr>
<td>Urine albumin/creatinine ratio</td>
</tr>
<tr>
<td>Serum calcium</td>
</tr>
<tr>
<td>Serum phosphate</td>
</tr>
<tr>
<td>Serum albumin</td>
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<tr>
<td>Serum bicarbonate</td>
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</tbody>
</table>

### Table 2 Modified Charlson score

<table>
<thead>
<tr>
<th>Comorbidity variable</th>
<th>ESKD comorbidity weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myocardial infarction</td>
<td>2</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>2</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>1</td>
</tr>
<tr>
<td>Cerebral vascular disease</td>
<td>2</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>1</td>
</tr>
<tr>
<td>Rheumatological</td>
<td>1</td>
</tr>
<tr>
<td>Peptic ulcer disease</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes without complications</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes with complications</td>
<td>2</td>
</tr>
<tr>
<td>Neoplasia</td>
<td>5</td>
</tr>
<tr>
<td>Moderate/severe liver disease</td>
<td>2</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>2</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>5</td>
</tr>
</tbody>
</table>

ESKD, end-stage kidney disease.

### Table 3 Survival prediction based on the modified Charlson score.

<table>
<thead>
<tr>
<th>Range of modified Charlson score (0–15)</th>
<th>Survival prediction</th>
</tr>
</thead>
<tbody>
<tr>
<td>9–15</td>
<td>&lt;3 months</td>
</tr>
<tr>
<td>6–8</td>
<td>3–12 months</td>
</tr>
<tr>
<td>4–5</td>
<td>12–24 months</td>
</tr>
<tr>
<td>2–3</td>
<td>24–60 months</td>
</tr>
<tr>
<td>0–1</td>
<td>&gt;60 months</td>
</tr>
</tbody>
</table>

### Table 2 Modified Charlson score

<table>
<thead>
<tr>
<th>Population validated for:</th>
<th>Dialysis patients (c-statistic = 0.653)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Simple bedside tool for prognosis14</td>
</tr>
</tbody>
</table>

**Advantages:**
- Not yet validated in ESKD on a non-dialysis pathway
- Better at predicting long-term survival than short-term survival for patients on dialysis15

**Disadvantages:**

The score for comorbidity is added to a score for age (one additional point for each decade beginning at 40 years).15

3. The Surprise Question

The Surprise Question: ‘Would I be surprised if this patient died in the next year?’ has been shown to assist clinicians in...

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identifying those patients for whom palliative care referral is appropriate. In one study in dialysis patients, the odds of dying within 1 year were 3.5 times higher in the ‘no’ patient group than the ‘yes’ patient group.16

**Population validated for:** Dialysis patients

**Advantages:**
- Introduces good clinical judgement17
- Easy prognostic tool to incorporate into clinical practice

**Disadvantages:**
- Weaker prognostic value than in combination with selected variables from the MCS (age, serum albumin level, dementia, peripheral vascular disease)

### 4. Predictive model combining the MCS and the Surprise Question9

Cohen et al.9 developed a simple prognostic model to assist in determining risk of death in dialysis patients by combining four routine variables – age, serum albumin, presence of dementia and peripheral vascular disease – together with the nephrologist’s answer to the Surprise Question. Combination of selected variables from the MCS and the Surprise Question had superior prognostic value than either tool independently.

**Population validated for:** Dialysis patients

**Advantages:**
- Simple bedside tool for predicting 6-month mortality
- Superior to using MCS or Surprise Question in isolation
- A ‘Surprise Question Predictor’ calculator incorporating the above variables with the Surprise Question is available from the website http://nephron.com. It is also available (at cost) as a download for iPhones and iPads. It succinctly estimates predicted survival at 6 months, 12 months and 18 months.

**Disadvantages:**
- Not yet validated in non-dialysis patients
- Low short-term positive predictive value versus model by Couchoud et al.18 (see below)

### 5. Clinical score to predict 6-month prognosis in elderly patients starting dialysis for ESKD18

Couchoud et al.18 developed and validated a simple clinical score in elderly (>75 years) ESKD patients to determine their 6-month prognosis should they commence dialysis. Interestingly, age was not associated with early mortality. Nine risk factors were identified and allocated points. Mortality rates ranged from 8% in the lowest risk group (0 point) to 17% in the median group (2 points) to 70% in the highest group (≥9 points) (Tables 4). This clinical score should be viewed as a tool to facilitate discussion with the patient and family as to possible prognosis.

**Population validated for:** Non-dialysis patients

**Advantages:**
- Simple bedside tool for predicting 6-month mortality if elderly ESKD patients started receiving dialysis

**Disadvantages:**
- High variability in mortality within each risk group, therefore, not appropriate to be used to withhold dialysis treatment from a patient but rather to facilitate discussion with the patient and family

### RENAL PHYSICIANS ASSOCIATION (RPA) GUIDELINES 2010 – THE USA

These recommendations are based on the expert consensus opinion of the RPA Working Group who performed systematic literature reviews relating to decisions to withhold or withdraw dialysis from adult and paediatric patients with acute kidney injury (AKI), CKD and ESRD. The guidelines incorporate the predictive models outlined above, with the exception of the Tangri et al. model.

According to the RPA Guidelines, it is reasonable to withhold dialysis treatment if the patient is over 75 years of age with two or more of the following risk factors:
- A response of ‘No, I would not be surprised if my patient died within the next 12 months’ to the Surprise Question.
- Patients with high comorbidity scores (e.g. MCS ≥ 8).
- Marked functional impairment (e.g. Karnofsky performance status score < 40).

#### Table 4 Risk factors for 6-month mortality for ESKD patients commencing dialysis

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Mortality points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body mass index &lt;18.5 kg/m²</td>
<td>2</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Congestive heart failure stages III to IV (New York Heart Association)</td>
<td>2</td>
</tr>
<tr>
<td>Peripheral vascular disease stages III to IV (Leriche classification)</td>
<td>2</td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>1</td>
</tr>
<tr>
<td>Active malignancy</td>
<td>1</td>
</tr>
<tr>
<td>Severe behavioural disorder</td>
<td>2</td>
</tr>
<tr>
<td>Total dependence on transfers</td>
<td>3</td>
</tr>
<tr>
<td>Unplanned dialysis</td>
<td>2</td>
</tr>
</tbody>
</table>

ESKD, end-stage kidney disease.
• Severe chronic malnutrition (serum albumin < 25 g/L using the bromcresol green method).

RECOMMENDATIONS

At present we suggest using the following predictive models and risk calculators for decision-making:

For CKD stage 3 to 5 patients:
1. The JAMA KFRE in patients with CKD stages 3 to 5.1

For patients being considered for a non-dialysis pathway (particularly the elderly):
1. The clinical score by Couchoud et al. involve mortality risk score obtained from nine risk factors.
2. The Surprise Question (despite lack of validation in this population).16

For dialysis patients being considered for transition to a non-dialysis pathway (particularly the elderly with comorbidities):
1. Inclusion of the Surprise Question into regular clinical practice for all dialysis patients, for example monthly patient review.16
2. The MCS.3,5,8
3. The clinical score by Cohen et al. involving a mortality score obtained from combining the answer to the Surprise Question with four routine variables – age, serum albumin, presence of dementia and peripheral vascular disease.9

Predictive modelling and risk calculators can provide a prognostic perspective and highlight the likely outcomes in this largely elderly population with multiple comorbidities and limited functional status. However, a predictive model that comprehensively incorporates variables relevant to the prognostic outcome of the non-dialysis population has yet to be developed. As such, we have made recommendations taking into consideration the strengths and weaknesses of pre-existing predictive tools. It is important to also recognize the weaknesses that currently exist with the development and use of multivariable risk prediction models.7

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QUALITY OF LIFE. WHAT INFORMATION IS ALREADY AVAILABLE AND WHAT EVIDENCE IS THIS BASED ON?

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• Patients with end-stage kidney disease (ESKD) are known to have a worse quality of life (QOL) than age-matched general population
• What constitutes a poor QOL of life varies from person to person and the potential impact of dialysis on an individual will be unique for each person
• Patients need good information in order to allow them to assess the potential impact of renal replacement therapy on their lives
• The Short Form 36 Health Survey (SF-36) QOL questionnaire is a suitable tool to be used in dialysis and non-dialysis patients to assess QOL changes

The quality of life (QOL) of patients with end-stage kidney disease (ESKD) is known to be worse than that of the general population.1–2 Although dialysis treatments aim to extend the life of the ESKD patient, survival is extensively influenced by age and comorbidities.3 Since the inception of dialysis in the 1960s and with technological advances, more patients had access to dialysis. In the last decade there has been more of a focus on the burden of dialysis, QOL and survival benefit. This article aims to promote the use of QOL tools and QOL discussion with kidney disease patients throughout their disease trajectory to assist in informed decision-making regarding dialysis decisions and promote research within the renal community.

WHAT IS THE EVIDENCE?

Hospital haemodialysis patients have reported worse QOL than patients treated with other renal replacement therapy (RRT), particularly transplantation.3–4 A number of factors have previously been identified to impact positively on QOL and include timely referral to a nephrologist,5,6 exercise during dialysis7–9 and optimizing renal anaemia.10 QOL is also described in the literature as a predictor of mortality and hospitalizations.11–14 Despite this knowledge, the assessment of QOL is not part of routine dialysis clinical practice in Australia or New Zealand.

Hamilton and Locking-Cusolito15 found significant positive relationships between dialysis adequacy scores using Kt/V and social/emotional QOL variables using the Kidney Disease Questionnaire. McMahon et al.10 found no change in physical variables with higher haemoglobins, but significant improvements in psychosocial variables with improved haemoglobins. Poorer physical and mental health scores, poor social support and psychosocial factors and self-reported depression are all predictors of hospitalization and mortality rates.11–14 In addition poorer QOL scores are reported as a better predictor of mortality and hospitalization than serum albumin.15 The physical dimensions of QOL are known to deteriorate with increasing age; however, studies by Garcia-Mendoza et al.16 and Rebollo et al.17 report less loss of QOL over time in the elderly patients compared with the younger patients. Elderly patients may readjust their life or health goals as their health declines. QOL is shown in studies to differ between dialysis modalities. The Broadening Options for Long-term Dialysis in the Elderly (BOLDE) study shows that although haemodialysis patients experience higher illness intrusion, elderly patients experience similar QOL whether on haemodialysis or peritoneal dialysis.18 It should still be kept in mind that QOL of dialysis patients is still reported to be similar to that of patients living with a terminal malignancy.19 Renal patients with a high symptom burden often have worse self-reported QOL.

Access to evidence-based literature regarding QOL on dialysis is important when presenting patients with the information they need to make a decision regarding RRT; although a QOL tool should not be used as a measure of whether someone should be accepted onto RRT. Dialysis should offer quality as well as quantity of life for the patients, but for the elderly, this may not always be the case,20 some elderly patients may favour quality over quantity of life.18 QOL is spoken about subjectively by patients during clinical discussions as a measure of the potential burden RRT may have on their current lifestyle.21,22 In the health research setting, the use of validated tools is helpful to prospectively document change in health status over time and identify potential relationships to other factors such as comorbid disease or biochemical markers.13,12,22–23

Access to treatment is an important issue where lack of transport may impact the patient’s decision on whether to commence treatment or not. Many Australian rural patients have to travel great distances or consider moving out of their home or live separately from family and loved ones in order to live close enough to access treatment. This will have a major impact on decision-making regarding whether to commence dialysis treatment or not for the patient, and their entire family and friend network.22

Commonly reported dimensions of QOL surveys are physical function, role limitations—physical, bodily pain, vitality, general health perceptions, role limitations—emotional, social function and mental health. These self-reported dimensions are influenced by a multitude of outside factors such as social situation, environmental factors, financial situation, symptoms experienced, personal values and psychological factors.24,25 Therefore it is important that patients self-administer their own QOL survey to avoid potential bias and invalidating the results. Staff cannot fill in forms for people with dementia, blindness or illiteracy because of potential bias. Availability of validated translated surveys would reduce the exclusion on non-English-speaking people. It is important there is no transference of clinician’s personal views on the patients QOL. Every person has a unique and individual perception of what QOL means to them personally, not as judged by someone else, entitling all patients and families to informed decisions regarding treatments.

Quality of life instruments widely used within the kidney disease population include the Short Form 36 Health Survey (SF-36), which measures eight generic variables in physical and psychological domains, with shorter versions available, the SF-20 and SF-12. Non English speakers should be accommodated for with translated versions of surveys where available. A renal specific survey, the Kidney Disease Quality of
Life (KDQOL), measures 20 variables, which include the eight SF-36 variables plus renal specific variables. It is available in two versions, the KDQOL-SF and KDQOL-36. The KDQOL has translated versions and is available through RAND Health.\textsuperscript{26} RAND Health is the research division of the non-profit institution the RAND Corporation based in the USA. A tool primarily aimed at the cancer population the Functional Assessment of Chronic Illness Therapy (FACT) has four QOL domains and over 50 different scales and symptom indexes to choose from including non-cancer measures, but none specifically for non-malignant chronic renal disease.\textsuperscript{27} The EQ-5D-5L (EuroQol) is a short generic QOL survey using five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) each with five levels of severity, and a visual analogue scale.\textsuperscript{28} The EQ-5D-5L is validated in six countries (excluding Australia but including New Zealand) with many language translations available. The World Health Organization QOL tool (WHOQOL-BREF) is another generic tool, which is recommended by Glover et al. (2011) for use where a generic tool is required; otherwise if a disease specific tool is required they recommend the KDQOL or one of its derivatives.\textsuperscript{24,29}

An Australian/New Zealand multi centre QOL collaboration would be useful with a single tool used, such as the generic SF-36, as a tool for both dialysis and non dialysis patients alike, or the longer renal specific KDQOL.

**SUMMARY OF THE EVIDENCE**

Continually striving to improve patient care through clinical management to improve factors such as haemoglobin and dialysis adequacy, and provide psychological support may impact on the patients QOL. The patient’s own perception on how dialysis will impact their perceived future QOL is an important consideration to be included in pre dialysis discussions. Poorer QOL and depression is associated with increased hospitalizations and mortality. Clinicians may be unaware that QOL for elderly patients on haemodialysis or peritoneal dialysis is similar. QOL of dialysis patients is similar that to patients dealing with a terminal malignancy, and is worse in renal patients with a high symptom burden. The impact of lack of access to health care through lack of transport must be considered in a patient’s dialysis decision-making as lack of transport can potentially have a significant impact on the patient’s perceived QOL.

**WHAT DO OTHER GUIDELINES SAY?**


UK Renal Association: No recommendation.

Canadian Society of Nephrology: Use of erythropoietic-stimulating agents. Anaemia is associated with reduction in QOL.

European Best Practice Guidelines: Indications for starting treatment with epoetin. Anaemia is associated with reduction in QOL and increased hospitalizations.

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In difficult cases Nephrologists should seek the advice of colleagues and, where available, a Bioethicist.

Medical ethics, like the law, can be intimidating to all medical practitioners, including Nephrologists. It may appear complex and driven by technical language. At its heart, however, it asks a simple question: in the circumstance of this patient what is the right thing to do? In the context of patients with end-stage kidney disease (ESKD) a fundamental question exists: is renal replacement therapy appropriate for the individual patient? If the answer is an automatic affirmative in all cases then that is one thing. If, on the other hand, a Nephrologist seeks to consider this question more carefully, ethics provides a structure, a system of thought that potentially assists towards a more nuanced answer to this question.

Bioethics provides several well-recognized approaches to the question of the appropriateness or otherwise of commencing or continuing dialysis. They include:

1. A balancing of the benefit versus the burden of therapy.
2. In the Caring for Australasians with Renal Impairment (CARI) Guidelines ‘Ethical Considerations’ the authors commence by stating:

The cardinal factor for acceptance onto dialysis or continuation of dialysis is whether dialysis is likely to be of benefit to the patient.

They elaborate:

An expectation of survival with an acceptable quality of life is a useful starting point for recommending dialysis.

This is a combination of objective and subjective factors. Another useful and authoritative guideline that seeks to assist Nephrologists in this deliberation is that issued by the Renal Physicians Association (RPA) of the USA. In their guidelines, the RPA set out specific criteria where they consider it ‘appropriate to forego’ or ‘reasonable to consider foregoing’ renal replacement therapy. Both the CARI and RPA guidelines expressly state that a decision to pursue a conservative pathway for a patient with ESKD was both medically and ethically valid.

2. An approach based on the principles of Bioethics – Autonomy, Beneficence, Non-Malefice and Justice.

Here, in addition to balancing benefit and burden (the second and third principles), the clinician needs to be conscious of both individual self-determination (in autonomy) and a general responsibility to society in the allocation of resources (justice).

A 78-year-old man with significant comorbidities and deteriorating functional status has ESKD. After careful deliberation the Nephrologist considers that dialysis would not be in the best interest of the patient. The patient is not convinced and insists on the commencement of dialysis stating: ‘I want dialysis . . . it is my right to have it.’

Does Autonomy trump the other principles? No. Autonomy is one of four principles. In the modern era the

**ETHICAL PRINCIPLES FOR PATIENTS, FAMILIES AND DOCTORS TO CONSIDER**

*Frank Brennan, Departments of Renal Medicine and Palliative Medicine, St George Hospital, Kogarah, New South Wales, Australia*

- An approach based on ethics can lead to better and more nuanced decision-making.
- Several guidelines on the initiation of and withdrawal from dialysis provide assistance in these deliberations.
- Each of the bioethical principles are important. Autonomy does not override the other principles.
principle of autonomy has been used to justify treatment that may not be appropriate on the basis of the view that the responsibility of medicine is to provide what the patients requests. All clinicians, including Nephrologists, have a responsibility to carefully balance the benefits and burdens of treatment, including dialysis and communicate that recommendation to the patient and family. The wishes and values of a patient should be considered but they should not, taken alone, be determinative. Ethically, a Nephrologist has a responsibility to provide treatment that they, after conscientious deliberation, feel is appropriate. They are under no ethical obligation to offer or provide treatment they feel is inappropriate to that individual patient.

The principle of Justice is also important. In terms of resources the CARI Guidelines Ethical Considerations is clear: ‘Decisions to recommend or not to recommend dialysis should not be influenced by . . . availability of resources . . .’

Finally it should be noted that occasionally a clinical situation can be complex, both ethically and medically challenging and where no easy answer is clear. In those circumstances it is extremely important for Nephrologists to feel comfortable in seeking the advice and counsel of their colleagues, other members of the Nephrology team and, when available, a Bioethicist. If there is an impasse in decision-making, patients have the right to seek a second opinion from another Nephrologist, either within or outside the original Renal unit and all parties, including the treating team have the right to bring the case for deliberation to the Supreme Court of the jurisdiction (see Section 10 Inappropriate Interventions).

The Plan should be used to guide health-care professionals in making treatment decisions if the individual is not competent to make decisions about their health care in order to participate in Advance Care Planning process, the education of patient and family around prognosis and treatment options is likely to be beneficial whether or not a plan is written or the individual loses decision-making capacity at the end of life.

• Facilitating Advance Care Planning discussions requires an understanding of their purpose and communication skills that need to be taught.

• Advance Care Planning needs to be supported by effective systems to enable the discussions and any resulting Plans to be used to aid subsequent decision-making.

WHAT IS ADVANCE CARE PLANNING (ACP)?

Advance Care Planning is a process of discussion and shared planning for future health care.1

Advance Care Planning involves the individual, a health-care professional and, if the individual wishes, family and/or significant others. An individual must be competent to make decisions about their health care in order to participate in ACP. ACP discussions may result in the formulation of an Advance Care Plan, which articulates the individual’s wishes, preferences, values and goals relevant to their current and future health care. This Plan should be accessible to health-care professionals involved in the individual’s care and to family or others as the individual deems appropriate. The Plan should be used to guide health-care professionals in making treatment decisions if the individual is not competent to do so. Given that individuals on dialysis have a mortality rate significantly higher than the general population,2 ACP is equally relevant to those who choose who renal replacement therapy and those who opt for supportive care.

Advance Care Planning may also result in the formulation of Advance Directives (AD) and/or the appointment of a legally nominated substitute decision-maker. AD are statements (usually written but can be oral in some jurisdictions) by an individual indicating their preference for or against a specific medical treatment, for example cardiopulmonary resuscitation or dialysis, in a specific circumstance.3 The section by Stewart and Brennan ‘Legal issues concerning withholding and withdrawal of dialysis’ discusses AD and substitute decision-makers in more detail. While the treating doctor may not be legally nominated as the substitute decision-maker, an individual may choose to indicate in their ACP that they would like to follow the medical recommendations of their doctor(s) in the event of loss of decision-making capacity or other more specific circumstance.

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doi:10.1111/nep.12065_5

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**WHAT ARE THE GOALS OF ACP IN CONSERVATIVELY MANAGED CHRONIC KIDNEY DISEASE (CKD) STAGE 5?**

When discussion of renal replacement therapy options results in the choice of conservative (non-dialysis) therapy there is an obvious opportunity to explore the patient’s goals for quality of life and how medical care can best serve these goals. ACP at this point provides an opportunity to explore the understanding of the patient and family about the prognosis for conservatively managed chronic kidney disease, accommodating the comorbidities of the individual. Information about the possibility of functional decline can facilitate appropriate contingency planning should the patient’s current living situation not meet their future care needs. It is also an opportunity to build a common understanding with the patient and family of when it would be appropriate to withhold or withdraw other life sustaining treatments in the context of terminal care for their kidney disease.

**WHAT ARE THE POTENTIAL BENEFITS OF ACP?**

**For the patient**

End-of-life wishes are more likely to be known and followed when individuals have been through the ACP process. Aggressive medical care near death in the setting of terminal illness has been shown to reduce patient quality of life in the last week of life. Cognitive impairment, and potentially loss of ability to make decisions about ones care, is common at the end of life meaning that if the patient is to participate in decisions about limiting treatment this often needs to be discussed in advance of the terminal phase of care. ACP can increase patient satisfaction with medical care. Feelings of isolation and lack of hope may be experienced with individuals are not able to honestly and openly discuss their hopes and fears for the future with loved ones. ACP provides an opportunity to ameliorate these feelings by starting discussion. ACP has the potential to facilitate culturally appropriate care by providing an opportunity for patients to express their cultural norms and protocols around end-of-life care and how they would like these observed.

Case example 1: Excerpt from the Advance Care Plan of Faith, a Maori woman receiving haemodialysis.

If I can no longer tell you myself I want those who care for me to know: . . .

I would like my cultural beliefs and values respected. I would like the hospital kaumatua [Maori elders] and Maori Catholic chaplain involved in my care. I would want them to observe appropriate process (e.g. prayers) over my body if I passed away in hospital, [including] before my body was moved.

**For the caregivers/family**

Making decisions for a loved one at the end of their life has been found to be a significant burden for those called upon to do so. Contributors to this burden include a need to make decisions under time pressure, reluctance to initiate discussions with the unwell person about end-of-life treatment preferences and conflict within a family about the appropriate course of treatment. Other factors that increase the burden experienced are problems with doctor-patient communication, poor continuity of care within a health-care system and uncertainty about prognosis.

Caregivers and family may experience better bereavement outcomes when the patient has not been exposed to aggressive medical interventions (e.g. artificial ventilation, resuscitation) near death and the burden of decision-making has been reported to be reduced when the individual or family feel well informed of the patient’s wishes. ACP has the potential to reduce the burden of decision-making on family members/caregivers because it provides an opportunity for the patient, family and health-care provider to reach a common understanding of the diagnosis, prognosis and goals and treatment preferences of the patient in the setting of deteriorating health with time to identify and understand uncertainty and conflicts of opinion. ACP also has the potential to improve continuity of care when health-care systems support the appropriate sharing of this information with other health-care providers.

Case example 2: Mrs A, a Samoan woman in her 60s receiving haemodialysis therapy.

Mrs A had significant comorbid medical conditions in addition to her renal failure including recurrent unexplained bleeding per rectum, persistent anaemia, chronic atrial fibrillation, rheumatic valvular heart disease, pulmonary hypertension and right ventricular dysfunction and obstructive sleep apnoea. She and her husband, both native Samoan speakers, attended a haemodialysis review clinic with Dr Y shortly after an admission with rectal bleeding. At this appointment Dr Y broached the subject of prognosis and whether she had considered her wishes in the event of deterioration in her health. Mrs A was quite upset and Dr Y called on her a few days later at dialysis when Mrs A explained that she and her husband had thought Dr Y was saying she had only days to live. Dr Y reassured Mrs A that this was not the case and they agreed that it would be best to have an interpreter at future appointments.

At her next review 4 months later Mrs A brought her daughter and an interpreter attended. The uncertainty of her prognosis was discussed again and Mrs A indicated that she did not wish to discuss her end-of-life care preferences with Dr Y but that she had done so with her family. Her daughter commented that it was really useful having the interpreter whose command of Samoan was much better than her own.

The following month Mrs A was found to have liver cirrhosis with complications including ascites and rectal varices,
her multiple medical problems made her unsuitable for intervention for the varices. Later that month Dr Y met with Mrs A in clinic, this time with her husband and her eldest son, the two people Mrs A identified as her chosen surrogate decision-makers, as well as an interpreter. From this consultation an Advance Care Plan emerged. Dr Y wrote a summary of the discussion on a hospital ACP pro forma. Dr Y met with Mrs A and an interpreter to go through this Plan and modified it with Mrs A. Mrs A then took written information (in English) on ACP home, along with her unsigned Plan. Mrs A met with her husband and five of her children at home and reviewed the Plan and information before returning the Plan for Mrs A and Dr Y to sign and enter in the hospital record.

Over the ensuing 6 months Mrs A deteriorated in health and was hospitalized recurrently. Four months after the plan was written she was referred to community palliative care services, largely for family support. It was identified that Mrs A had a strong desire to be reacquainted with a child who had been adopted out and was living overseas. The community palliative care team and Dr Y were able to assist with the paperwork required to expedite this person’s immigration visa. Mrs A withdrew from dialysis 6 months after writing her Plan when it became technically impossible to achieve an adequate treatment. She was cared for at home surrounded by her family and with input from community palliative care services until her death.

Although Mrs A was competent to participate in the decision to withdraw from dialysis and her written Advance Care Plan was therefore not referred to, the process of ACP was felt by nephrology staff and the family to have been worthwhile. The nephrologist conducting the final family meeting in hospital commented that the family and patient were very well prepared. Mrs A’s eldest son, reflecting on her death 6 months later, commented that the plan was the ‘best thing ever’. It articulated what their mother wanted rather than what they thought she wanted, particularly the importance of her spirituality and faith. He felt that having had the opportunity to reunite his mother with his brother was especially valuable. His mother had also communicated with them how she wanted to spend her last days after she stopped dialysis and they shared some special time fulfilling these wishes for her.

This case shows that the value of ACP is not necessarily in the written Plan or in any AD limiting treatment. Mrs A pursued all active treatment options available to her and withdrew from dialysis when it was no longer feasible. The achievement of ACP in Mrs A’s case was bringing her and her immediate family to a common understanding with nephrology staff about the seriousness of her medical conditions, her prognosis and the potential scenarios for future deterioration in health, despite a language barrier and a busy family who were not all available during office hours. Knowing that her life expectancy was limited, Mrs A identified and articulated, largely to her family, her personal goals and preferences for care. Her family were able to choose to spend time with her and support her, knowing this might be a limited opportunity. Mrs A’s case shows that these conversations can be difficult but when ACP is started when the patient is relatively well and out of hospital there is the opportunity to identify misunderstandings, resolve them and move forward. Furthermore there is time for patients to reach a point of readiness to undertake ACP and identify key decision-makers and personal priorities. Starting ACP early was key to reuniting Mrs A with her son. Mrs A’s ACP also highlights some issues to be aware of when using interpreters. Both Mrs A and her family commented to Dr Y that the skill of interpreters in translating these conversations was variable but unfortunately Dr Y could not consistently secure their preferred interpreter. The better interpreters were able to convey information better than some of Mrs A’s children felt they could. Language barriers within families can be a significant issue for some, particularly where older patients have children who grew up in New Zealand or Australia and may be more comfortable speaking in English than their parent’s first language.

**WHAT ARE THE BARRIERS TO ACP?**

**Patient barriers**

1. Patients may wait for physicians to initiate end-of-life discussions and may feel uncomfortable asking for prognostic information.7
2. Patients may perceive ACP as a health-care professional initiative to limit their future medical treatment, for example because of resource constraints.3,9
3. Patients may not be aware that their condition is life limiting.

**Family/caregiver barriers**

1. Family may wait for the patient to initiate end-of-life discussions.8
2. Family may be unaware that the patient has a life limiting medical condition.

**Clinician barriers**

1. Discussing death can be emotionally distressing for health professionals and skills and/or support for managing this distress are not currently commonly taught to nephrology trainees.10,11 The previous experience of emotional distress during end-of-life conversations may cause the health-care professional to avoid future discussions.10
2. Lack of available time to hold ACP discussions.10
3. Physician perceptions that end-of-life conversations are not valuable to the patient and/or may cause harm by diminishing patient hope.10
Lack of skills, particularly communication skills, to effectively facilitate patient-centred decision-making.\(^2\)

**Organizational barriers**

1. To overcome the barriers above organizations need to facilitate training and support for their staff in acquiring the skills necessary for effective ACP.
2. Organizations need to value ACP by allowing adequate time and space for these conversations to take place.
3. To maximize the potential benefit of ACP there need to be organizational systems to store written Advance Care Plans and make them available to treating clinicians, for example in the Emergency Department.

**TIMING OF ACP**

Advance Care Planning may be appropriate at a number of different stages in the trajectory of chronic kidney disease. There is an excess mortality risk conferred by having chronic kidney disease per se,\(^3\) so it is arguable that ACP is relevant to anyone with chronic kidney disease. In particular for those between 65 and 84 years we know that the risk of death from an alternative cause exceeds that of reaching different stages in the trajectory of chronic kidney disease. \(^4\) CKD is also associated with a greater rate of cognitive decline in the elderly.\(^5\) If ACP discussions are to take place in elderly or comorbid patients they may therefore need to be initiated earlier in the trajectory of renal disease than the physician would usually begin discussing options for dialysis or conservative care, particularly following an acute illness or if there is clinical suspicion of early cognitive impairment.

**DOCUMENTATION**

To fulfil the promise of achieving patient goals for end-of-life care, ACP discussions must be documented and stored in such a way that they are accessible to not only the regular family doctor and nephrologist but also health-care staff providing acute care. There needs to be provision for education of health-care professionals about the existence of Advance Care Plans, when to refer to them and in what circumstances AD apply.

**REVIEW**

The treatment preferences of an individual may change over time, particularly with changes in their social circumstances, health or functional status. For this reason it is important that ACP is regarded as an ongoing process with facility for regular review of any Advance Care Plan, AD or expressed patient preferences to confirm that they still reflect the wishes of the individual.\(^6\)\(^\text{16}\) There also needs to be a facility for updating Advance Care Plans stored in the clinical record. Those who initially decline ACP may wish to participate at a later date and it should be clear to the patient that they can reopen the discussion at a later stage and how they might go about doing so.
APPROPRIATE ASSESSMENT OF SYMPTOM BURDEN AND PROVISION OF PATIENT INFORMATION

Frank Brennan,1 Brian Siva2 and Susan Crail3,
1Departments of Renal Medicine and Palliative Medicine, St George Hospital, Kogarah, New South Wales, 2Fremantle Hospital, Fremantle, Western Australia, and 3Central and North Adelaide Renal and Transplantation Service, Adelaide, South Australia, Australia

- Patients with end-stage kidney disease (ESKD), with or without renal replacement therapy (RRT), are heavily burdened with symptoms that may interact and compound each other. The burden of symptoms experienced by patients on dialysis is rarely mentioned in patient information sheets despite being well documented in research data.
- There are significant barriers to medication use in ESKD including a lack of knowledge of pharmacokinetics in dialysis and conflicting information about drug dose and safety.
- There is a growing body of literature on the symptom management of patients with ESKD.
- Patients need clear information about the potential effects dialysis and non-dialysis pathways on symptom burden and how this can change with time.
- Standardization of tools used to collate information about symptoms can assist in the provision of information to patients. We recommend the Patient Outcome Scale symptom module (Renal Version) tool (accessible via the kcl.ac.uk website) for assessing symptom burden.

Patients with end-stage kidney disease (ESKD) whether or not on renal replacement therapy (RRT) have considerable prevalence of symptoms. Indeed this group is among the most heavily burdened of any disease group.1–3 A large, systematic review of prevalence studies of symptoms,4 experienced by dialysis patients showed a significant burden of symptoms. A subsequent study by the same group found a similar prevalence of symptoms in patients being managed conservatively.5 A summary of the results of those studies appears below in Table 1.

In addition to individual symptoms, it is important to note that patients may experience multiple symptoms simultaneously. These may be from multiple sources, some from the renal failure (e.g. pruritus and restless legs), from comorbidities (e.g. diabetic peripheral neuropathy, diabetes-related gastroparesis, angina) or be related to dialysis therapies (intradialytic hypotension, cramping, sleep disturbance from automated peritoneal dialysis alarms). Also, the interaction of individual symptoms may exacerbate other problems. For example, the simultaneous presence of nocturnal uraemic pruritus, restless legs syndrome and pain secondary to arthri-

<table>
<thead>
<tr>
<th>Symptom prevalence [%]</th>
<th>Dialysis</th>
<th>Conservative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue/tiredness</td>
<td>71</td>
<td>75</td>
</tr>
<tr>
<td>Pruritus</td>
<td>55</td>
<td>74</td>
</tr>
<tr>
<td>Constipation</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Anorexia</td>
<td>49</td>
<td>47</td>
</tr>
<tr>
<td>Pain</td>
<td>47</td>
<td>53</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>44</td>
<td>42</td>
</tr>
<tr>
<td>Anxiety</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>35</td>
<td>61</td>
</tr>
<tr>
<td>Nausea</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Restless legs</td>
<td>30</td>
<td>48</td>
</tr>
<tr>
<td>Depression</td>
<td>27</td>
<td></td>
</tr>
</tbody>
</table>

Symptoms experienced by patients with ESKD are consistently underassessed and inadequately managed. In addition to the experience of the individual symptom itself, some symptoms (e.g. uraemic pruritus) have been shown to be associated with reduced quality of life and a shortened life expectancy.6 Symptom burden is likely to alter and increase over time for patients choosing either a dialysis or non-dialysis pathway and therefore needs to be regularly reassessed. In the experience of the St George’s Hospital Renal Unit, New South Wales, in approximately one-fifth patients, symptoms are not improved by initiation of dialysis. In the Renal Supportive Care clinic at this unit, two-thirds of the patients who attend are on dialysis and one-third are following the Renal Supportive Care pathway, showing also the symptom burden of those dialysing. Anecdotally, some patients may have very few symptoms, regardless of management choice and stage of disease. The inherent unpredictability of symptomatology in this context means that ongoing and regular assessment is essential.

Pain is highly prevalent among dialysis patients7 although poorly recognized and often underreported by patients. Up to 50% of haemodialysis patients report pain when directly questioned, a similar percentage to those on the non-dialysis pathway.1 In the month before death, this prevalence rises to over 70%.4 Very few resources available for patients about dialysis mention this and death from kidney failure is often described as painless. The rise in reported pain may be an indicator of approaching the end of life for some patients.

Prevalence of restless legs may be difficult to assess because of previously poorly defined diagnostic criteria. The International Restless Legs Syndrome Study Group defined the following four features for diagnosis:
1 The desire to move the legs in association with unusual or uncomfortable sensations deep within the legs.

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<table>
<thead>
<tr>
<th>Symptom</th>
<th>Medication</th>
<th>Other comments</th>
</tr>
</thead>
</table>
| Pain                    | 1. Mild pain – Paracetamol 1 g qid. Safe and effective.  
2. Moderate pain – Tramadol with a dose reduction. For dialysis patients 50 mg bd–100 mg bd (max.). For conservative patients CKD 5–50 mg bd (max.).  
3. Severe pain – Hydromorphone, Fentanyl, Buprenorphine  
Methadone are considered safe. Oxycodone may be used but in ESKD patients being managed conservatively. commence in small doses (1.25 mg–2.5 mg). | For an excellent overview see Reference 13.  
Authorities advise to commence with low doses and titrate to efficacy and side-effects.  
Pain management should commence with an analysis of aetiology. This may be multifactorial.  
Pain management is complicated by the complex pharmacology of analgesic medications in the context of ESKD.  
A multidisciplinary approach consisting of Nephrology, Pain Medicine, Palliative Care and other relevant disciplines is advised.  
For neuropathic pain may need other classes of medications including TCAs, and Gapperntoids.  
Ensure that the patient does not have another cause for pruritus (e.g. allergies, scabies).  
Skin moisturisers advised.  
If patient presents with both UP and RLS commence Gabapentin.  
Main side-effects of Gabapentin are blurred vision and drowsiness.  |
| Uraemic pruritus (UP)   | Gabapentin,14,16  
Dialysis patients – commence 100 mg after each dialysis and titrate to efficacy and side-effects.  
Non-dialysis patients – CKD stage 5 – 100 mg every second night;  
If CKD 3- or 4- start at 100 mg nocte & titrate to efficacy and side-effects.  
Evening Primrose Oil 17,18 1 capsule bd.  
Thalidomide19 – 100 mg nocte.  
UV-B therapy20  
Topical capsaicin 0.025%.21,22 May not be tolerated because of transient burning feeling on the skin. | Take careful history to establish whether the patient fulfills the international diagnostic criteria (see above).  
If patient presents with both RLS and UP commence Gabapentin.  
Often multifactorial in origin.  
Metoclopramide acts as both a central anti-emetic and a peripheral pro-kinetic. The latter action is useful with uraemic or diabetic gastroparesis.  
Check causative medications.  
Add fibre to diet  
Often multifactorial.  
May include Cardiac disease, Respiratory disease, fluid overload and anaemia. |
| Nausea                  | Metoclopramide 5–10 mg tds before meals.  
Haloperidol 0.5 bd.  
Cyclizine 25 mg tds. | Often multifactorial.  |
| Constipation            | Coloxyl and Senna. |  |
| Dyspnoea                | Principal first step is to exclude reversible causes (see accompanying comments).  
Management  
Hydromorphone – commence 05 mg qid then increase if tolerated.  
Benzodiazepine – e.g. Lorazepam 0.5 mg bd sublingually and 0.5–1 mg prn if a severe episode of dyspnoea. | Often multifactorial.  |
| Anorexia                | Treat reversible precipitants.  
Review by Renal Dietician.  
Supplementary drinks. |  |
| Fatigue                 | Treat the reversible cause(s).  
Reassurance to the patient and family of the ubiquity of this symptom in patients with ESKD. | Multifactorial.  |
| Anxiety                 | Counselling.  
Psychologist/Psychiatry review.  
For panic attacks consider Benzodiazepines – e.g. Lorazepam 0.5 mg–1 mg sublingually stat. |  |
| Depression              | The SSRI's that are safe to use without the need for dose adjustment are Citalopram, Fluoxetine, Sertraline.  
Also consider TCAs ‘in treatment – resistant depression’.27 | May be difficult to diagnose – the constitutional symptoms of ESKD are identical to several of the diagnostic criteria for Major Depression.  
When in doubt seek a Psychiatry review.  
Multifactorial.  
If suspect sleep apnoea – Formal Sleep Study.  |
| Sleep disturbance       | Careful history taking to find a cause.  
Treat the cause.  
Temazepam 10 mg 20 mg – nocte. |  |

qid, four times per day; tds, three times per day; bd, twice per day; nocte, at night; prn, as required; CKD, chronic kidney diseases; UV-B, ultraviolet-B therapy; SSRI, selective serotonin reuptake inhibitors; TCA, tricyclic antidepressants.
2 Motor restlessness in an effort to remove these sensations.
3 Symptoms become obvious or worse at rest and may be temporarily diminished by voluntary movement.
4 Symptoms occur most frequently in the evening or early part of the night (this may be different in dialysis patients experiencing this problem while dialysing).

It appears to be more prevalent in the conservatively managed group rather than in dialysis patients and may increase in severity as death approaches.\(^5\) It may affect quality of life through sleep disturbance and is only occasionally mentioned in patient information leaflets.

Pruritus is common in both dialysis and conservatively managed patients and may be particularly severe in haemodialysis patients towards the end of, or just after a dialysis session. It is often mentioned in patient information leaflets on chronic kidney disease but rarely mentioned in dialysis discussions and patients may not be aware that starting dialysis may not solve this problem. In a large Dialysis Outcomes and Practice Patterns Study (DOPPS) report,\(^6\) up to 50% of haemodialysis patients reported moderate to severe pruritus, a similar to percentage to those in stage 4–5 chronic kidney disease (CKD) not on dialysis.\(^8\) Knowledge of this may alter the patient’s decision about whether to dialyse but also highlights the need for the nephrologist to ask dialysis patients about this symptom and offer treatment.

Tiredness and lack of energy are common symptoms and may be a marker indicating patient decline. They are difficult to define and may therefore be difficult to assess and manage. They are common on dialysis and many older patients describe severe tiredness after a dialysis session. Depression may be a contributing factor and is found in approximately 20% of haemodialysis patients\(^9\) and 40% of conservatively managed patients with stage 5 CKD.\(^10\) The use of erythropoiesis-stimulating agents to improve haemoglobin levels is of benefit in these patients and can help to alleviate symptoms.

**SYMPTOM ASSESSMENT**

Meticulous and careful assessment and treatment of symptoms, based on rigorous evidence can improve the severity of the symptoms. In terms of assessment, there are several validated symptom inventory tools that allow both patients and clinicians to efficiently concentrate on the symptoms causing the most difficulty. Those tools include:

- **Patient Outcome Scale symptom module (Renal Version).** Designed for use in advanced disease and validated in renal disease. This simple one page tool is used widely and is recommended as the tool of choice. It is available through the King’s College, London website (http://wwwcsi.kcl.ac.uk/files) in forms for patients, staff and carers to fill-in.
- **Edmonton Symptom Assessment Score.** Uses a visual analogue scale to assess both physical and emotional symptoms.\(^11\)
- **Dialysis Symptom Index.** Adapted from the Memorial Symptom Assessment Score originally for cancer patients. Shown to be a reliable tool for assessing symptoms in dialysis patients but not validated in conservatively managed CKD.

Standardization of tools used to assess symptom burden may allow data comparison between units, consolidating a broader evidence base to assess the success or failure of interventions.

**SYMPTOM MANAGEMENT**

In terms of treatment, there are no international evidence-based guidelines on symptom management in ESKD. Nevertheless, several authoritative reviews of the management of individual symptoms have been published.\(^12\)\(^13\) A short summary of those reviews, including the most recent and highest level of evidence in symptom management, follows in Table 2. For further information see the website of the St George Hospital Renal Department under Palliative Care.

For symptom management of the dying patient, see section by Dr Urban, Models of Care – End of Life Pathways.

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**REFERENCES**

HOLISTIC PALLIATIVE CARE APPROACH – PHYSICAL, SPIRITUAL, RELIGIOUS AND PSYCHOLOGICAL NEEDS

Frank Brennan, Departments of Renal Medicine and Palliative Medicine, St George Hospital, Kogarah, New South Wales, Australia

- The palliative approach to patients with end-stage kidney disease (ESKD) includes all aspects of the physical, emotional and spiritual dimensions of the illness and care of the family.
- Health professionals dealing with patients with ESKD need to acquire skills in these areas.
- Continuing collaboration between renal medicine and palliative medicine is essential.
- The cultural and religious beliefs of patients may inform or determine their view on medical decision-making including in relation to the withholding or withdrawing of dialysis and the care of the dying.

The definition of palliative care by the World Health Organization is:

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.

The definition is very broad and represents the maturation of thinking within the discipline as to its role. Pertinent to the management of patients with end-stage kidney disease (ESKD) is the reference to ‘life-limiting illnesses’, which includes patients with ESKD, the concentration on the early identification of issues rather than waiting until the terminal phase before introducing a palliative approach and, finally, the breadth of concern – from the physical to the spiritual. That breadth perfectly accords with modern medical beliefs in the inter-relatedness of body, mind and spirit in the experience of illness for all human beings. Given that no one health professional can provide all treatment, support and assistance needed a critical ethos of the palliative approach is the multi-disciplinary team.

The other focus of care is the family. Certainly, in the context of ESKD, the family play a pivotal role, often over many years of support, both practical and emotional to the patient. Here the role of the Renal Social Worker is critical is supporting the family in all relevant ways.

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Given that there is currently, and will for foreseeable future be, a shortage of palliative care health professionals the onus should be on all disciplines, including Nephrology, to acquire and nurture basic skills in the palliative approach to patients. In the context of patients with ESKD those competencies should include skills in discussions around the possible withholding of and withdrawing from dialysis, symptom
management, psychosocial support and the appropriate care of the dying patient. To that end, collaborations between Renal Medicine and Palliative Medicine continue to grow.

SPIRITUAL AND RELIGIOUS PERSPECTIVES ON ILLNESS AND DEATH

An 85-year-old Greek-Australian man is married with five children. He is a devout Greek Orthodox. He has multiple co-morbidities and develops worsening renal function. Dialysis is commenced. Shortly after commencing dialysis he struggles with worsening fatigue, vascular access issues, debilitating Herpes Zoster and a series of Transient Ischaemic Attacks. He discusses withdrawing from dialysis. He worries that this would be suicide and contrary to his faith. One of his daughters says to him: ‘Dad, when you die is in God’s hands, not yours. You cannot stop.’

Human spirituality is not simply religious faith. Human spirituality is a universal attribute that reflects the unique and precious nature of each individual. In broad terms, spirituality is a sense of self and meaning. Spiritual issues are often prominent in persons with illness, including ESKD – Why is this happening to me? Am I more than my disease and its management? Is there any meaning in my suffering? What will happen to me when I die? These are profound issues and there is a clear role in the care of patients with ESKD of Pastoral Care workers, Social Workers or Chaplains.

In the modern era patients may or may not have a specific religious faith. That faith may inform or determine medical decision-making. In the context of ESKD faith may enter pre-dialysis discussions, during dialysis, discussions around mortality and bereavement.

Australia and New Zealand are multicultural and multireligious societies. In terms of the cultural and religious perspectives on serious illness such as ESKD, dialysis and death several points are fundamental:

1. In modern societies patients may or may not have a religious faith. All patients have spirituality.
2. It is important to avoid two approaches:
   a. Ignoring all cultural/religious diversity and applying one approach to all patients.
   b. Assuming that all patients from an ethnic background or religious faith will act or believe identically. An example would be thinking ‘All Chinese patients believe this . . .’.
3. Cultural and religious beliefs may enter discussions at critical times in the trajectory of chronic kidney disease including pre-dialysis discussions, during dialysis, discussions around withdrawing from dialysis and the care of the dying patient. It is important to enquire whether the medical decision-making is influenced partly or completely by religious beliefs as they need to be clarified and examined. An example is where there is concern that withdrawing from dialysis constitutes suicide or be a serious affront to a deity. It is appropriate to encourage the patient or their family to seek the guidance of religious clerics or advisers within their faith.

A short summary of the perspectives of the major world religions on serious illness and death follows. It is not possible to refer to all religions. In a clinical context, it is important to seek the perspective of the individual patient and family as, even within the one body of faith, there may be divergent views.

CHRISTIANITY

As there are a large number of denominations within the Christian faith, generalizations are difficult to make. Nevertheless, there is a common belief that Jesus Christ is the Son of God, that He rose from the dead and that there is life after death. Attitudes to serious illness and death vary from acceptance to distress. Withdrawal from treatment, including dialysis is acceptable in Christian ethics. It is not seen as sinful or constituting suicide. Intentionally causing a patient to die is forbidden.

JUDAISM

The Jewish faith believes in one God and that the human body belongs to God. With that belief comes an obligation to heal. Jewish law is binding and Jews may wish to consult a Rabbi before making serious medical decisions. Withdrawal from treatment, including dialysis is acceptable in Jewish law and ethics if it is in the patient’s best interests. Suicide and euthanasia are against Jewish law.

ISLAM

‘Islam’ means submitting to the will of God. Muslims, the followers of Islam, believe in one God. Prophets guide the faithful and the most influential was Muhammad. They believe that God spoke through Muhammad in the Qur’an. Muslims believe in life after death, that suffering is part of God’s plan and accept death as His will. Islamic law permits the withdrawal of life-sustaining treatment, including dialysis if it is in the patient’s best interests. In this instance withdrawal of life-sustaining treatment is seen as allowing death to take its natural course. Suicide and euthanasia are against Islamic law.

HINDUISM

Hinduism is a broad range of beliefs with rich traditions. A common belief is that death leads to reincarnation, life in heaven or absorption into Brahman (the ultimate reality). Suffering, including an illness such as ESKD may be seen as punishment for wrongs committed in the past. A good death is an important part of spiritual life. Broadly this is defined as dying in old age, having resolved conflicts, said goodbye and having placed all one’s affairs in order. A bad death is untimely, violent and unprepared. Some Hindus will fast as they approach death as purification of body and spirit. There may be tension between open disclosure to allow a person to
prepare for death and the desire of the family to protect the loved one. Analgesia and sedation may be declined in order to maintain a clear mind.

BUDDHISM

Buddhism preaches the inevitability of death. ‘Buddhists tend to be psychologically prepared to accept impending death with calmness and dignity’. The withdrawal of treatment, including dialysis, is acceptable. In Buddhism there is an emphasis on mindfulness and mental clarity. To that end, Buddhists may decline analgesia or sedation with the belief that dying with an unclouded mind can lead to a better rebirth. Individuals are encouraged to follow their own conscience in decision-making as there is no central authority competent to pronounce on matters of ethics or doctrine.

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REFERENCES


RECOMMENDED READING


INAPPROPRIATE INTERVENTIONS IN THE DYING PATIENT

Brian Siva1 and Frank Brennan2, 1Fremantle Hospital, Fremantle, Western Australia, and 2Departments of Renal Medicine and Palliative Medicine, St George Hospital, Kogarah, New South Wales, Australia

• A core competency of Nephrology should be the capacity to diagnose dying.

• Withdrawal of dialysis is ethically and legally valid.

It is a fundamental tenet of medical practice that a careful balance should be always made between the benefits and burdens of any treatment.1 Far from being static, this is a dynamic process. That is especially so when the condition of the patient is rapidly and irreversibly changing and where a treatment that was once considered absolutely beneficial is now of no or marginal benefit only.

In the context of end-stage kidney disease (ESKD) this process of dynamic decision-making reflecting the dynamic of the clinical circumstances of the patient is extremely important. Multiple issues may unfold – related or unrelated to the underlying ESKD and its management – that may alter the clinical circumstances necessitating a review of all treatment.

DEATH

Significant sentinel events such as overwhelming sepsis, cardiogenic shock, significant arrhythmia or cerebrovascular events may result in the patient dying.

Further, that competency should also include its corollary – to consider the withdrawing of active medical care such as antibiotics, inotropes, parenteral feeding and, ultimately, dialysis itself. Failure to do this or procrastination in this process of recognition may result in neither the clinicians nor the family being prepared for the possibility of death. That unpreparedness may have a significant impact on the bereavement of the family.

MALIGNANCY

The other clinical scenario that may unfold is the patient with concurrent ESKD on dialysis and metastatic malignancy. Reaching a point in the trajectory of the underlying malignancy where active treatment, including the process of dialysis itself, becomes more burdensome and less sustainable, is a matter of careful clinical judgement and negotiation with the patient. Difficulties arise if no discussion occurs, no plans set in place and a situation, already challenging, becomes driven by crisis or unrealistic expectations on behalf of the patient, family and treating clinicians.

DIALYSIS WITHDRAWAL

Withdrawal from dialysis is common with 467 people in Australia and 66 people in New Zealand withdrawing from dialysis in 2010 (ANZDATA (Australian and New Zealand Dialysis and Transplantation) report 2011, Chapter 3). A total of 186 of the deaths in Australia and 20 of the deaths in New Zealand patients withdrawing from dialysis were recorded as due to psychosocial issues.

It is important to note, as stated in the Ethics section of this paper, that the withdrawing of treatment that is considered inappropriate is ethically and legally valid. It is neither suicide nor euthanasia. Nor does it constitute medical abandonment. The psychology of withdrawal for the patient and family may be fraught and requires careful and sensitive communication, coupled with an active pursuit of comfort and the appropriate management of the terminal phase or, in the context of dialysis withdrawal where the exact time of death may be indeterminate, the post-withdrawal phase leading to the patient’s death.

AUTOMATED IMPLANTABLE CARDIOVERTER DEFIBRILLATOR (AICD)

One area of some controversy is the use of Automated Implantable Cardioverter Defibrillator (AICD) in patients with ESKD as a preventative measure for sudden cardiac death (SCD). There is no doubt that there is a beneficial role of an AICD for prevention of SCD in high-risk populations.
Patients with ESKD are often excluded from pivotal AICD trials and therefore, the role of this device in the ESKD population is uncertain.

Sudden cardiac death is common in ESKD and often multifactorial as a result of underlying cardiac dysfunction (hypertrophy and ischaemia) and metabolic and haemodynamic insult. In the absence of any effective medical therapy to prevent SCD in the dialysis population, the use of AICD is an attractive one. The only data available are a retrospective study showing a 42% reduction in death risk in ESKD patients with an AICD as a secondary preventative measure. No randomized controlled trials are available. Other studies suggest that the mortality rate of chronic kidney disease and ESKD patients remains high despite an AICD and complication rates of this device are higher compared with the non-ESKD population. Therefore, the use of an AICD as a life-prolonging intervention in ESKD patients is controversial because the absence of clear survival benefit.

In the trajectory of ESKD, a decision may be made that the continuation of an AICD is not in the patient’s best wishes or contrary to their stated goals of care. Those times may include the point where death is imminent or likely, where a decision is made to withdraw from dialysis for whatever reason, where the device is no longer considered effective, where multiple shocks occur related to disease progression, significantly worsening cardiac disease or cognitive impairment and patient preference. Usually, the object of care has shifted to a principal focus on the comfort of the patient, rather than attempting to prevent death from arrhythmia. In that circumstance, it may be medically appropriate to deprogramme an AICD.

Ideally, a discussion with the treating Cardiologist about the possible circumstances of deprogramming should occur at the time of implantation. As part of gaining the informed consent of the patient a full and clear explanation should be given of the limitations of AICD therapy and the potential for deprogramming. In addition to the situations of crisis or change in focus of management described above, these discussions should also occur at the time of advance care planning and discussions surrounding cardiopulmonary resuscitation (CPR) orders. Those discussions may be conducted by many clinicians, including Nephrologists.

The legal and ethical issues raised by deactivation are identical to those raised by the withholding or withdrawing of all medical interventions. Critically, it is important to note that deprogramming AICDs does not constitute euthanasia or physician-assisted suicide, that deprogramming AICD will not cause death and that the process of deprogramming is not painful or make the process of death more painful.

The process of deprogramming should involve collaboration among the relevant health professionals, including the treating Nephrologist. Ideally, all centres and physicians who implant AICDs should have a formal pathway to undertake deprogramming.

**SUMMARY**

In summary, decisions regarding interventions that may prolong survival of patients with ESKD need to be individualized where survival benefit needs to be weighed against the cost of the procedure, complication rates and the patient’s quality of life and life expectancy.

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**REFERENCES**


**RELATED DOCUMENTS**


**RUNNING AND SETTING UP A RENAL SUPPORTIVE CARE PROGRAMME**

Mark Brown1 and Cathy Miller2, 1Departments of Renal Medicine and Medicine, St George Hospital and University of NSW, Sydney, New South Wales, Australia; and 2Palliative Care Service, Department of General Medicine, North Shore and Waitakere Hospitals, Waitemata District Health Board, Auckland, New Zealand

To date no consistent model of care has been available for supporting patients and their families on a conservative non-dialysis pathway. Broadly speaking the UK appears to have embraced this pathway more than most other countries but
even there, there are divergent views on what models of care should be implemented. One model, developed at St. George hospital in Sydney, is as follows:

The Renal Supportive Care team oversees a programme deliberately titled ‘HOPE: Helping Older Patients with End-stage kidney disease’. The multidisciplinary team is essentially an integration of Renal and Palliative Medicine, using the skills of both disciplines to ensure optimum nephrology care while adding a focus on symptom control, holistic physical and spiritual care and, when appropriate, the facilitation of a ‘good death’.

The team consists of:
1. Renal Supportive Care clinical nurse consultant.
2. Palliative care physician.
3. Research assistant.
5. Renal advanced trainee.
6. Social work and dietician support.

In most Units new funding is generally required for 1–3 above while involvement in this programme can generally be facilitated for an already funded nephrologist and advanced trainee. Depending on the level of other work additional funds may also be required for social work and dietician support.

The key elements of the programme are:
1. Nurse or other clinician initiated referral to renal palliative care as needed.
2. A dedicated Renal Supportive Care clinic, which is additional to usual nephrology clinics. The nephrologist does not attend this clinic.
   a. Two clinics per week and inpatient services.
   b. Palliative care specialist as part of the renal department runs the clinic.
   c. The clinical nurse consultant (CNC) and renal registrar attend the clinic; the CNC spends time with the patient and family to address symptoms using a validated symptom inventory.
   a. The clinic is supported by a dietician & social worker as needed.
   b. The focus is on integrated holistic patient care.
   c. The clinic provides registrar training in this aspect of renal and palliative medicine.
3. An outreach consultative service to a rural site.
4. Development of ‘palliative care’ treatment list for end-stage kidney disease non-dialysis management. This is available for use by any staff at any hour through online access at http://stgrenal.med.unsw.edu.au/

   Performance measured currently used to evaluate the service are:
1. Uptake of the service by patients – this evaluates whether the service is meeting the needs of patients but also whether nephrologists and nursing staff are referring patients as needed.
2. Improvement in the symptom burden of patients.
3. Improvement in patient’s quality of life, formally assessed by a validated tool.
4. Patient, family and carer satisfaction with the service.
5. Education – it is important that the service shows a commitment to education in the Renal Unit then to other Units and the broader medical and general community.
6. Research – Renal Supportive Care remains a poorly studied aspect of renal medicine and programmes should have systematic research programmes built in to improve knowledge and thereby future patient management.

While this is one model of care it will not be possible to implement this in every Renal Unit across Australia and New Zealand because of lack of funding and available staff, particularly palliative care physicians. Another model to be considered is for the development of a small number of Units such as this described above, to become so-called ‘Centres of Excellence’ – probably a better term would be ‘RSC training centres’. In this way, existing staff in a Renal Unit could spend time in one of these centres to learn about management of patients on a non-dialysis Renal Supportive Care programme and take that knowledge back with them to their Unit. In such cases it is likely that a Renal Supportive Care CNC position would still be required in each large Renal Unit to ensure the success of such a programme.

Other models will undoubtedly be developed and will be successful. The importance is that whatever model is used the focus should be on ensuring optimum nephrology care while adding a focus on symptom control, holistic physical and spiritual care and, when appropriate, the facilitation of a ‘good deaths’, all of this underpinned by assessment of service performance as outlined above.

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MODELS OF CARE – END OF LIFE PATHWAYS

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• Resuscitation status and Advance Care Plans need to be discussed and clearly documented
• The Liverpool Care Pathway is a recognised model of end-of-life (EOL) care, and has been adapted for patients with end-stage renal disease
• Recognition of a dying patient allows initiation of a multidisciplinary EOL pathway such as the Liverpool Care Pathway for hospital inpatients, and for support for families if a home death is planned. A fall in performance status is an indicator of decline.

End-stage kidney disease (ESKD) is associated with high levels of morbidity and poor prognosis. Despite this, end of life care for these patients is variable. An essential part of caring for these patients (especially on the conservative management pathway) should include ensuring a good death. End of
life care incorporates four key domains of care, physical, psychological, social and spiritual (Table 1) and supports the family at that time and into bereavement. The Liverpool Care Pathway (LCP) was developed for patients dying of terminal cancer (mainly in the acute hospital setting – although also transferable to the community) and has been shown to be transferable to patients dying from cerebrovascular accident or heart failure.\(^1\) The LCP is an integrated care pathway designed for the care of patients who are in the last days/hours of their life, to facilitate effective planning and provision of care during this critical time. The challenge is to ensure best practice in end of life care in the renal failure setting. In the UK, a Steering Group was set up to determine if the LCP was transferable to patients with chronic kidney disease (CKD), and a Renal LCP document was formulated with prescribing guidelines.\(^2\)

**What needs to be done?**
- Advance care planning – desired place of death? (fully covered in Section 6 Advance Care Planning)
- Essential components of End-of-Life care:\(^3\)

1. **Diagnosing dying**
2. **Communication with patient and family**
3. **Assessment of needs and symptoms and management – practical guidelines/prescribing**
4. **Regular review of symptoms and patient/family needs**
5. **After-death care**

**Advance care plan/desired place of death**
This is more fully discussed in section 6. Ideally patients’ wishes for the care they receive should be known prior to the dying phase as often time is limited and resources need to be rapidly mobilized. An important part of this is enquiring about where a patient would prefer to die. In one study, 36% of ESKD patients expressed a desire for a home death\(^4\) yet most of these patients die in hospital. Planning for end of life care at home is difficult as preparing and supporting a patient and family for a home death can be time and resource consuming, and requires a level of coordination and sharing of knowledge and experience that is not always easy to achieve. Thus early knowledge that this is a patient’s wish is essential.

**Essential components of EOL Pathway**
The LCP (see example at http://www.liv.ac.uk/mcpcil/) is mainly useful in the acute inpatient setting to assist non-Palliative Care specialist teams to ensure a good death for all their patients. It has some essential components which translate to the end of life setting for any illness. These components make up the model of care (Table 2). Here these are broken down and practical advice on prescribing for end of life in CKD given. As previously mentioned, a Renal LCP has been developed in the UK.

### 1 Diagnosing dying

Uncertainty is an integral part of dying. Often patients who are expected to die survive much longer than expected, while some people die suddenly, however without the recognition that a patient may be dying, EOL management cannot be put into place. Unfortunately there are several barriers to diagnosing dying and thus to access to good EOL care.\(^3\)

**Barriers:**
Hope the patient may improve
Pursuance of futile interventions
Disagreement about the patient’s condition
Failure to recognize key symptoms and signs
Lack of knowledge about how to care for/prescribe for dying patient
Poor ability to communicate
Concerns about foreshortening life
Concerns about withholding treatment
Cultural and spiritual barriers

Signs which are usually associated with the dying phase in cancer:
- Patient is bedbound
- Semi-comatose or unconscious
- Able to take only sips of fluid
- No longer able to take oral medication\(^3\)

The predictability of the dying phase is not always so clear in other chronic life-limiting illnesses. A recent study however showed the trajectory in conservatively managed ESKD to be similar to that of malignancy, in that the Karnofsky Performance Status is relatively stable with a rapid decline in the 1–2 months prior to death.\(^5\) Theoretically, this means that there will be an indication for most patients that death is approaching, and the above criteria can be applied to these patients. Because the decline towards death is rapid, EOL services need to be rapidly responsive to changing functional status, and care needs to be provided in the patient’s preferred place of care. An important element to diagnosing dying is that the members of the multidisciplinary/multi-professional team caring for the patient agree that the patient is likely to die. Once dying is diagnosed, an EOL pathway can be initiated. The patient’s resuscitation status must be reviewed and a ‘not for resuscitation’ order should be instated. The UK expert consensus group determined that patients with an eGFR equal to or below 30 mL/min who are in the last days of life would be appropriate for the Renal LCP.\(^2\)
Care of the dying patient:

2 Communication
An assessment of the patient and their family’s understanding of their current condition needs to be made. Issues around dying need to be raised sensitively and appropriately. It can be useful to have these discussions with a social worker also present for support. Avoiding the use of ambiguous language is important. If relatives are informed clearly that the patient is dying, they have the opportunity to ask questions, contact relevant people, say their goodbyes and stay with the patient if they wish. Communication with other healthcare providers, especially the primary care team (the patient’s GP), is essential if a home death is planned. Resuscitation status should be updated and explained to the patient and family.

3 Assessment of needs and symptoms and management
The LCP for the Dying Patient (or a similar site-specific document) can be used for patients dying from any cause. This is a multi-disciplinary tool with guidelines for assessment and appropriate management at the end of life. Initial assessment includes diagnosis and baseline information about symptoms and swallowing/continence, the patient’s ability to communicate, spirituality, nutrition and hydration and skin care. Patients with ESKD may still pass urine and the requirement for an indwelling catheter should be reviewed. Dying patients will not open their bowels frequently, however if discomfort arises due to constipation then bowel care (including enemas) is essential. Regular mouth care to ensure a clean and moist mouth is more important to comfort than hydration.

It is known that patients with conservatively managed ESKD have a symptom burden similar to terminal cancer or end-stage heart failure. Achieving control of pain, dyspnoea, nausea, respiratory secretions and terminal agitation are essential in the renal failure setting as they are in terminal malignancy. Prescribing guidelines require adjustment in the renal failure population due to the accumulation of many medications which are renally excreted. The guidelines for LCP prescribing in advanced kidney disease is a valuable resource.

Nausea and vomiting:

<table>
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<tr>
<th>Table 2 Essential components of end of life care</th>
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<td><strong>Diagnosing dying</strong></td>
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<td><strong>Communication</strong></td>
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<td><strong>Symptom/needs initial assessment</strong></td>
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<tr>
<td><strong>Management plan</strong></td>
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<td><strong>Regular review</strong></td>
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<td><strong>After-death care</strong></td>
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Haloperidol is recommended for uraemia-induced nausea and vomiting starting with a dose at the lower end of the effective range and titrating according to response and CNS effects due to possible accumulation of active metabolites (start 0.5 mg s/c bd).

Levomepromazine can be used if symptoms persist however it is more sedating. Starting dose 3.125 mg subcutaneously bd or tds – contact Palliative Care team for advice.

Metoclopramide should be used with caution due to accumulation and potentially increased risk of extrapyramidal side effects (although may be more useful in patients with gastroparesis – maximum 30 mg per 24 hours).

Cyclizine may cause hypotension or arrhythmia in patients with cardiac co-morbidities (although this was when used intravenously) so is not recommended.

Constipation:

Respiratory Tract Secretions:

It is important to determine the cause of secretions – anticholinergic medication is unlikely to improve fluid overload/acute pulmonary oedema or secretions due to lower respiratory tract infection. Explanation to the family is crucial as the patient is often not distressed by the secretions and treatment can have undesirable side effects such as dry mouth and urinary retention. Glycopyrrolate does not cross the blood-brain barrier therefore does not cause sedation or delirium as hyoscinehydrobromide can (not recommended), thus it is first choice. Dose should be reduced to 50% of normal due to increased anti-cholinergic side effects and (e.g. 100–200 μg prn s/c q4h).

Terminal agitation:
Midazolam may be used for agitation in the dying phase. Dose and timing interval adjustments may be required in advanced kidney disease due to accumulation of conjugated metabolites.\textsuperscript{11}

Clonazepam (0.5 mg bds/subcut or sublingual), haloperidol and levomepromazine (6.25–12.5 mg prn – maximum 200 mg per 24 hours) can also be used.

**Pain and dyspnoea:**

Opioid prescribing can be difficult given that most opioids have metabolites which are renally excreted and accumulate in renal failure, and that some patients may be on opioids prior to entering the terminal phase. This means in practice that opioid choice and dose/interval must be individualized to each patient. Morphine and oxycodone have metabolites which accumulate and can be toxic, and thus cannot be recommended.\textsuperscript{12}

*Hydromorphone* has been controversial as its metabolite hydromorphone-3-glucuronide accumulates in renal failure and is known to be neuroexcitatory in rats, however evidence in humans is lacking. It is not recommended in the UK guidelines, however is likely to be safer than morphine or oxycodone.

Generally *fentanyl* is the safest opioid to use given that its renally excreted metabolites are inactive,\textsuperscript{2,13} however given its short half-life, can be impractical. In an opioid-naïve patient, 25 µg subcutaneously prn q2 hourly is an appropriate starting dose. If more than three doses per 24 hours are used, a fentanyl continuous infusion may be required. If fentanyl is unavailable, hydromorphone 0.25 mg subcutaneously prn q4 hourly can be used. If a regular dose is needed, it is best to start with a longer interval, for example 0.25 mg s/c qid initially, titrating based on use of breakthrough medication. In a patient already receiving background opioid, advice from the specialist Palliative Care Team should be sought. Fentanyl patches take 12–24 hours to reach effective plasma levels and are thus not useful to initiate in the terminal setting where rapid titration may be required, however if they are already in situ then they should continue provided they are not causing adverse effects.

*Methadone* is another opioid which may be used in renal failure, however due to its large pharmacodynamic and pharmacokinetic inter-individual variability, should be prescribed with experienced specialist supervision. In severe renal impairment a dose reduction of 50–75% is recommended.\textsuperscript{14}

4 After death care

Some patients will have spiritual, religious or cultural needs in relation to care for their body after death, and these should be met wherever possible. It is important to care for the family and friends of the deceased patient. Information with regards to contacting the bereavement service and funeral director should be given. Discussion regarding patient valuables, viewing of the body, post mortems and organ donation may be needed. Some families may require information about child bereavement services. Other professionals who have been involved in care of the patients, especially the GP, should be informed of the death.\textsuperscript{3,3}

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CULTURAL CONSIDERATIONS WHEN PROVIDING CARE TO ABORIGINAL AND TORRES STRAIT ISLANDERS OPTING FOR CONSERVATIVE CARE

Cerian Sajiv, Alice Springs Hospital, Central Australian Renal Services, Alice Springs, Northern Territory, Australia

- Highest rates of chronic and end-stage kidney diseases occur within remote, regional and indigenous communities in Australia.
- Advance care planning is not common practice for most Aboriginal and Torres Strait Islander (ATSI) people.
- There are many barriers to providing effective supportive care to ATSI people.
- Choice of place of death: being able to ‘finish up’ in the place of their choice is very important to many indigenous Australians.
- Family meetings, preferably in the presence of a cultural broker to explain treatment pathways and care issues will lead to informed choices being made in an environment where all stakeholders are able to participate freely.
- Each indigenous person is different and should not be stereotyped.

DEFINITION OF AN ABORIGINAL AND TORRES STRAIT ISLANDER

As highlighted by Sullivan et al.,¹ these are people who have descended from an ATSI ancestor, who identify as ATSI and are accepted as such by the community in which they live.

However, indigenous Australians are not a homogenous group but instead belong to a very diverse group of culturally different communities. Across indigenous Australian communities it is evident that there are strong ties to community, land or country and family.¹

In Australia, the highest rates of chronic and end-stage kidney diseases occur within remote, regional, indigenous communities characterized by rapidly changing lifestyles, relative poverty and disadvantage. Cass et al.² have shown that although not all indigenous groups are affected equally by end-stage kidney disease there are some communities where the rates are about 20 times higher than the national figure, accelerating over the past few years in conjunction with coexisting conditions of type II diabetes and ischaemic heart disease (Fig. 1, Table 1).

Information about patients who decline renal replacement therapy and opt for the ‘Conservative pathway’ is more difficult to access, however one small survey earlier by Cattford³ found that 35% of Aboriginal end-stage renal failure patients living on South Australia’s Anangu Pitjantjatjara Lands had refused treatment. Recent data on this not available, however, as evident in the Chronic Kidney Disease database in Central Australia, the number of patients declining renal replacement therapy in this region are currently lower than the figures suggested above.

Culture is an important part of the context within which all people including healthcare professionals understand their world and make decisions about how to act. In their articles Paul⁴ and Muller and Desmond⁵ have shown that along with personal psychology and life experiences, culture fundamentally shapes the way people make meaning out of illness, suffering and dying.

Failure to take culture seriously may mean that we elevate our own values and fail to understand the value systems held by people of different backgrounds. In addition these studies⁴,⁵ indicate that this may lead to problems such as lack of trust, increased desire for futile aggressive care at the end of life, unnecessary physical/emotional and spiritual suffering.
lack of faith in the physician, lack of adherence to the treatment regimen and dissatisfaction with care.

ADVANCE HEALTH DIRECTIVES AND ADVANCE CARE PLANNING IN INDIGENOUS AUSTRALIANS

In an ideal situation, for patients who choose the non-dialysis pathway, clinicians should discuss advance directives and advance care planning with the person and their family members to document the goals of care.

Unlike their Western counterparts, advance care planning is not common practice for most ATSI people. Some will not see the necessity to draw up an end of life plan due to sensitivities around issues of death. Oprah Fried\textsuperscript{7,8} in her reflections from Central Australia has commented that nearly all would want to die at home or on their ‘country’. ‘Country’ refers to a particular area of land where they and their ancestors were born, lived and died.

Sullivan \textit{et al.}\textsuperscript{1} in their study have highlighted several barriers to providing effective supportive care to ATSI people. These include: poor literacy and education levels; high mobility; poor housing and overcrowding; high levels of domestic violence and substance misuse; low income levels; poor underlying health; fear and dislike of hospitals, of the health system and officials; fear and distress of non-indigenous people coming to their homes and remoteness.

Challenges in creating advance directives include factors involving trust, uncertainty, hope, presence of multiple clinicians, communication issues including adequacy of communication, the willingness of clinicians to follow patient preferences, patient and family misunderstandings about the process, documents not available when needed.

Family meetings are usually a good way to interact with the indigenous patient and the family. Effective communication skills are needed to have effective discussions. Here the clinician needs to actively listen and give time for replies and questions. Patients and families should not feel unduly pressured to choose or embark on a particular pathway of care. It can be helpful to let the caregivers know that this is a medical recommendation and that the physician is, with their assent, primarily responsible for the decisions. Above all it should be a shared decision making process with the patient’s best interest the primary consideration at all times.

It is important to discuss cultural requirements and preferences early in the conservative management pathway so that the impact of family and kinship relatives can be managed. Family/kinship rules may mean that certain family members of an indigenous person, who in mainstream society would be regarded as distant relatives, may have strong cultural responsibilities to that person. It is imperative therefore to identify early in the planning stages who is the culturally appropriate person, or persons to be involved in the decision making process so that they can give consent for treatment and discuss goals of care.

Where English is not the main language of the person and/or their family, interactions and family meetings will always need to be held in the presence of a cultural broker (aboriginal liaison officer) and or an interpreter to explain treatment pathways and care issues so that informed choices can be made.

\begin{table}
\centering
\begin{tabular}{|l|l|l|}
\hline
State/territory & Estimated indigenous population, by state/territory, Australia, 30 June 2011 & \\
\hline
 & Indigenous population, number & Proportion (%) of indigenous people by state/territory & \\
\hline
NSW & 168 773 & 2.3 & \\
Vic. & 37 647 & 0.7 & \\
Qld & 164 883 & 3.6 & \\
WA & 77 694 & 3.4 & \\
SA & 31 040 & 1.9 & \\
Tas. & 20 580 & 4.0 & \\
ACT & 4 825 & 1.3 & \\
NT & 69 855 & 30.3 & \\
Australia & 575 552 & 2.6 & \\
\hline
\end{tabular}
\caption{Estimated indigenous population, by state/territory, Australia, 30 June 2011}
\end{table}
are made. Informed choices can be only made in an environment where all stakeholders can participate freely. An interpreter or translator can be an invaluable resource in such situations to ensure that information is conveyed and received accurately. The use of a family member as an interpreter may not always be appropriate and the health care team should be sensitive to these issues.

Given the remoteness and accessibility issues in the life of indigenous Australians, it may be sometimes difficult to bring the patients to the ‘tertiary services’. In many instances, ‘services’ may have to be taken to the patient. One effective way of doing this is by tele or video case-conferencing with the local clinic, DMO/primary GP, patient and family as well as the renal team in attendance. The range of environmental and social conditions in the remote setting may also necessitate flexible models of care and creative solutions to sourcing equipment and medications etc.

Patients in the ‘remote setting’ who have chosen the non-dialysis pathway will have to be supported and cared for at home. However, as Fried7,8 has shown conditions for the delivery of health care differ markedly between the remote desert region’s of Central Australia as compared with major Australian cities. Palliative care services in conjunction with the primary care and renal teams should play a role in educating community members in how they can support the person and the family, thus helping to meet the person’s choice of place to ‘finish up’ and helping family/community members feel they have appropriately supported the patient in the ‘finishing up’ process. As recommended by the American Society of Nephrology, Galla9, there is a clear need to strengthen partnerships between palliative care and renal services if the best care and support is to be provided for a person opting for the non-dialysis pathway.

Choice of place of death: being able to ‘finish up’ in the place of their choice is very important to many indigenous Australians, with strong connections to traditional lands playing an important cultural role. However cultural practices and requirements may vary from community to community, and even within communities (particularly in urban areas). If a patient wishes to stay on or return to their homeland to die, these arrangements will need to be planned and supported.

The effectiveness of renal supportive care may also strongly correlate with issues such as: person not being able to fully understand their illness; difficulties in communication and the length of time it takes to gain a person’s trust.

Each indigenous person is different and therefore should not be stereotyped. One should not make assumptions of ATSI people and remember that each case is considered on an individual basis, without prejudice or judgement.

Establish a commitment to the patient, build trust and be consistent.

Respect ATSI cultural protocols, practices and customs.

Respect ATSI decision-making processes. For most indigenous people having the family involved is extremely important. Families, as mentioned above can include an extensive range of relatives. However there are individual variations.

Institutions such as hospitals and dialysis units, nursing homes must take responsibility for facilitating culturally competent care. This includes knowing the groups that most frequently use the institution, seeking out and disseminating information about cultural beliefs that might affect attitudes towards illness and health care, providing adequate translation services, and identifying community resources. Hiring and training health care workers (at all levels) who are members of the ethnic group in question or knowledgeable about them and who have credibility within these communities may assist greatly in bridging the cultural chasm.

Health professionals need to acknowledge the beliefs and practices of people who differ from them in age, occupation or social class, ethnic background, sex, sexuality, religious belief and disability. They need to acknowledge their own culture as different from those of the people they serve, to ensure that they do not impose their beliefs on the minority communities.

Cultural safety requires providers from the majority culture to challenge their own stereotyped views of a minority culture. It promotes positive recognition of diversity.

Even when physicians and patients try to plan for the future, advance directives are easily misunderstood or misinterpreted. Clear decision-making contributes to quality of life at the end of life, and its absence may lead to worse outcomes. Trust, the confidence that the clinicians is acting unselfishly in the patients interest, is fundamental to effective medical care, particularly at the end of life.

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CULTURAL CONSIDERATIONS WHEN PROVIDING CARE TO NEW ZEALAND MĀORI OPTING FOR CONSERVATIVE CARE

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Hīnga atu ana he Totara
Ara mai ana he Totara
As the mighty totara tree falls
So another grows to stand in its place
(Proverb recited by Faith, a Māori woman on dialysis, when asked how she felt about having life limiting illness. To her this represents how when she passes away others from her whakapapa (lineage) will stand in her place.)

There is significant variation between cultural groups in the way the end of life is discussed and handled.1 This guide does not seek to be an exhaustive resource on Māori cultural practices as they apply to health care or the end of life. Dr Stallworthy is a New Zealander of European descent and a renal physician with an interest in renal supportive care and Advance Care Planning. Ms Glavish is from the Ngati Whatua iwi (Māori tribe) and is Chief Advisor-Tikanga (Māori protocol) for Auckland and Waitemata District Health Boards in New Zealand. Where statements in this section are based on Ms Glavish’s expert opinion this is noted by ‘(NG)’ following the statement. For Māori, as within any culture, there will be variation in the preferences of any individual influenced by iwi (tribal) variation, degree of urbanization of the individual and his or her whānau (extended family), ethnic diversity and personal experience among other factors. In the interest of assisting health care professionals to provide culturally safe care,2 this section seeks to provide an awareness of some common Māori cultural practices which may differ from non-Māori practices and thus hopefully enable the health care professional to offer patients and/or whānau the opportunity to observe protocols which are significant to them. This is particularly important as an individual approaches the end of life because of the emotional intensity of this time for the patient and family. All New Zealand District Health Boards have kaumātua (elders) on staff to advise on local practice and support Māori patients and whānau. Fostering a good relationship with these individuals and services may facilitate feedback to a renal unit on areas in which they are providing culturally sensitive care and opportunities for improvement.

WHARE TAPA WHĀ
As set out in the Hospice New Zealand Standards for Palliative Care, palliative and end-of-life care should aim to encompass more than the relief of physical symptoms.3 When providing end-of-life care to Māori it may be helpful to use the holistic Māori concept of ‘hauora’ or well-being. Hauora has been described by a Māori author, Mason Durie, as a meeting house, the Whare Tapa Whā.4 The Whare Tapa Whā is built on the whenua (land or roots), the side walls are composed of the taha tinana (physical health) and the taha whānau (family and social well-being) while the roof is formed by the taha wairua (spiritual well-being) and taha hinengaro (mental and emotional well-being). Thus for many Māori, particularly when discussing issues as potentially sensitive as treatment preferences and end-of-life care, it will be important to address whānau, spiritual and psychological well-being as well as physical illness. The communication skills which assist with good advance care planning (ACP) and palliative care, such as recognizing and responding to emotional cues, are likely to be appreciated by Māori as an acknowledgement of the importance of taha hinengaro. Ways in which we can facilitate Māori patients including taha whānau and taha wairua in their management are mentioned below.

NIHO TANIWAH AND KARANGA AITUĀ
Naida Glavish, Chief Advisor-Tikanga (Māori protocol) for Auckland and Waitemata District Health Boards, explains a Māori view of the cycle of life which she calls ‘niho taniwha.’ This cycle begins and ends in ‘wāhi rangaro’, the place unseen, perhaps equivalent to a spirit world, and in between are a series of stages, each with its own responsibilities and duties, from mokopuna (grandchildren) to tamariki (children), mātua (adults), kaumātua (elders) and tūpuna (ancestors), then back to mokopuna (NG). This world view acknowledges that death is an ever present part of life, perhaps in contrast to Western culture which has been described as death denying.5 Both Ms Glavish and Nikora et al.6 describe the exposure to death at tangi (Māori funeral ceremonies) from childhood as an important learning process. Despite this acknowledgement of death there is also the concept of ‘karanga aituā’ or tempting fate and calling ones death forward by discussing it.7 This does not necessarily extend to disclosure of a life limiting prognosis but may influence willingness to discuss timeframes, care at the time of death and the dying process (NG). As recommended in other guidelines for communicating around life limiting illness, it is important to ascertain the information needs of the individual to avoid disclosing more or less than the individual is ready to hear.7 Some, particularly older, Māori may prefer that these discussions are held with whānau (NG), a situation which is not uncommon in other cultures but which may feel uncomfortable for health care professionals accustomed to placing patient autonomy at the pinnacle of their ethical framework.8

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ADVANCE CARE PLANNING

In Māori culture the locus of decision making rests with the individual, usually with whānau input, while they remain competent, although some may prefer whānau to take on this role as noted above (NG). It is important for the health care professional to establish whether the patient feels comfortable discussing prognosis and end-of-life issues before embarking upon discussion but also to be aware that belief in karanga aituā may underlie reluctance. However, Nikora et al. note that decision making after death is often easier for whānau when the deceased has previously made their wishes known, suggesting that in Māori society the wishes of the individual are used to inform whānau decision making, at least after death. To facilitate whānau involvement and support there needs to be enough warning that a discussion is planned for whānau to attend if possible. ACP may be seen by Māori patients as a way to assist whānau with future decision making or it can be used as an opportunity to make health care professionals aware of the cultural practises that will be important to them in their final days and after death (see case example in section 6 on Advance Care Planning). There is currently work underway by the Māori Tools Task Team of the New Zealand Advance Care Planning Co-operative on ACP tools with a Māori focus. The need for this has been endorsed by the ‘Kia Ngāwari: Investigating the end-of-life experiences and cultural needs of Māori and their whānau’ research project led by Dr Tess Moeke-Maxwell of Waikato University. This research is still being analysed but the patient cohort includes Māori with renal failure and in preliminary analysis it has been identified as a concern that Māori whanau do not always appreciate that renal failure, even for those who choose renal replacement therapy, is a life limiting condition (personal communication, Dr Tess Moeke-Maxwell). Engaging Māori patients and whānau in the open discussion of illness and prognosis that is part of ACP is one way to address this issue.

WHĀNAU/FAMILY MEETINGS

The Māori concept of whānau is generally more inclusive than the New Zealand European concept of family. Family meetings are often appreciated and well attended. Even small children may be included. Providing sufficient space for a dozen or more people can be helpful and at least one New Zealand renal unit has a collection of toys for children to play with during whānau meetings. Inviting whānau to open a meeting with a karakia or prayer can be an opportunity to respect the importance of taha wairua. As with any family meeting, it is likely to be helpful to ask all those present, including hospital staff, to introduce themselves and their role at the beginning of the meeting. There will often be a whānau spokesperson or people who will be identified by whānau (NG). When decisions are being made by whānau the goal is to reach consensus or kotahitanga. When this is not achieved the whānau usually defer to more senior family members. Silence or withdrawal from the discussion often represents protest or dissent rather than agreement. It is usually appropriate to offer the opportunity for whānau to close a meeting with a karakia, particularly if they have chosen to open with one. Clinicians may also find it helpful to offer the opportunity for patients to say karakia at the beginning and/or end of one-on-one consultations if the content is anticipated or transpires to be emotional and/or culturally sensitive, for example if whānau have not been present during ACP conversations or when breaking bad news.

PENDING DEATH AND TŪPĀPUAKU

Many Māori will prefer to die at home and whānau often prefer to take their terminally ill relative home, although, as with other groups in society, the pressures of urbanization and geographical spread of modern whānau mean that this should not be assumed. When an individual prefers to die on their tūrangawaewae (tribal land) this may be geographically distant from their current place of residence and/or rural. Good palliative care is likely to be facilitated by a health care professional assisting the patient and whānau with finding appropriate health care services in their chosen place of death, for example identifying a local general practitioner and referring to local palliative care services. Community palliative care services may be more acceptable than inpatient hospice care to many Māori. In hospital or hospice, whānau and patients should be offered a single room and access to appropriate spiritual and cultural support. An autopsy can be particularly distressing to Māori it is appropriate to prepare whānau in advance if referral to the coroner and/or autopsy is likely to be necessary and explain why.

Care of the tūpāpuaku (deceased) can be a particularly sensitive area as it is generally highly ritualized in Māori culture. Whānau may have specific cultural and spiritual practices they wish to observe around handling of the body, including washing and dressing and staying with the tūpāpuaku as they progress from the ward, to the mortuary and to the funeral director then marae. The way in which the tūpāpuaku is transported is also significant to many Māori, for example wrapped in allocated linen, feet first and following a pre-determined route away from public thoroughfares. Blessing the room the tūpāpuaku died in with a karakia prior to cleaning may also be appropriate. Again seeking advice from local kaumātua and specifically asking whānau is likely to be the best way to avoid causing inadvertent offense by breaching protocol.

OTHER SPECIFIC CULTURAL PRACTICES

Individual patients and whānau may wish to use rongoā (traditional Maori methods of healing) to achieve their goals...
of care. Considering the Whare Tapa Whā model, rongoā may be valued for their contribution to aspects of well-being other than physical health.

Local kaumātua (elders) can advise on local practice. The handling of food, taonga (valuables), the head and human waste are areas to be aware of. Generally, food and medicines for human consumption should be kept separate from items for general use, for example microwaves or refrigerators should be used for either food preparation/storage or non-food uses (e.g. heating wheat bags), not both, tea towels should only be used for drying dishes and tables should not be sat on. The head is considered tapu (sacred) so passing food over the head, touching the head without asking permission or using the same pillows for the head as the body can cause offence. Human waste, bed pans and urinals should be placed, handled, stored/disposed of separately in time and space to other items, particularly food.9

Attempting to correctly pronounce Māori names is polite and appropriate.

CONCLUSION

In the words of another Māori proverb:

*Ki mai ki ahau, he aha te mea nui o te ao, māku e kīi atu – He Tangata, He Tangata, He Tangata.*

When I am asked what is the greatest treasure on earth I will reply – it is the people, it is the people, it is the people.

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ISSUES AND MODELS OF RENAL SUPPORTIVE CARE IN RURAL AREAS

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- Patients in rural areas are both economically and medically disadvantaged.
- Access to specialist services in rural areas is limited. More care is likely to be out-sourced to local physicians, GPs and palliative care nurses who will need ‘on the ground’ outreach support from renal/palliative care services.
- Referral to these services may low due to knowledge of availability and previous exposure of the referring physician to the use of these services.
- Developments in information technology (telemedicine) are likely to play a significant role in management, education and advice in these specialist areas.

For the purpose of this position statement rural is defined as areas outside of the major cities. In Australia approximately one third of the population live in rural areas (Fig. 1). The Accessibility/Remoteness Index for Australia (ARIA) is used to define rural and remote but it has significant inequities and is not supported by the Rural Doctor Association for resource allocation.

Although the medicine is similar in rural and urban environments the application is different in rural settings. The challenges involved in organizing specialist care palliative care to rural areas compared with major urban areas relate to differences in environment especially population density and distances, infrastructure and resources. Palliative care services have generally developed in major population centres.

Rural areas are characterized by a lack of specialist and well organized palliative care services. Palliative care in rural areas is generally delivered by primary care physicians and community nurses and not palliative care specialists. Renal palliative care potentially involves a further skill set that may not be in the general practitioners or even all palliative care specialists’ tool boxes.

In a review of studies in rural palliative care Evans *et al.* found that access to specialized palliative care services is a problem,2–4 that rural patients reportedly were less likely than their urban counterparts to receive care from a hospice service,3 that families and professionals have difficulties in accessing information6,7 and that communication difficulties can occur between primary care and specialists.8

Patients both indigenous and non-indigenous living in rural areas are both economically and medically disadvantaged. Grace *et al.* in a review of ANZDATA listed patients starting dialysis between 2000 and 2010 found only 7% of postcodes outside of major cities were in the most advantaged quartile, compared with 54% of postcodes within
major cities Gray et al. in a similar review of non-indigenous patients on dialysis found significant differences in disease burden between major capitals (MC), inner remote (IM), outer remote (OM) and very remote (VR) areas – Figure 2.10

Patients want to be treated close to where they reside to avoid the cost of travel and dislocation involved in visiting metropolitan based clinics. The implementation of renal palliative/supportive care services in rural areas requires a different model to metropolitan areas if these patients are to have the same standard of care as those in metropolitan areas.

General practitioners and renal physicians tend to refer on the basis of previous personal exposure. Providing specialist renal palliative/supportive care services will need to involve some on the ground outreach services to gain the trust and respect of the local physicians. Any model will need to enhance contact between palliative care services and local physicians. A ‘move aside while we show you how it is done in the city’ approach is unlikely to be successful. The knowledge base for renal palliative care will need to be outsourced to the local physicians, GPs, and palliative care nurses to enhance patient care.

Given that it is unlikely that rural units will have specialist renal palliative/supportive expertise on site the DNT committee supports the concept of a hub and spoke model of care to provide equity of service in all rural and remote areas. This implies that metropolitan palliative care services will have a responsibility to provide outreach services and will need adequate resources. The same model is used to provide transplant services successfully in rural areas and not only allows rural patients to access these services locally but provides up skilling of the local workforce.

Developments in information technology such as telemedicine are possible solutions to some of the problems associated with distance and isolation. The current Medicare rebate for consultations by videoconferencing should promote and compensate set up costs. This can be easily performed with currently available technology including Skype.

There is a potential role for web based on going education for rural renal physicians and palliative care physicians in renal supportive care. This could potentially involve cased based scenarios in a chat room environment.

Fig. 1 Population distribution, Australia (RAMA classification). IR, inner regional, MC, major city, OR, outer regional, VR, very remote.
A model currently working in the New England Area involves having a local supportive care nurse who is experienced in dialysis assess all patients referred to the service. Referrals can be from nursing colleagues, GPs, allied health workers and renal physicians. Although initially conceived to support patients who elect to proceed on a non-dialysis pathway the service now includes all patients with chronic kidney disease. A visiting palliative care specialist from St George Hospital provides an outreach service as well as phone advice, support and ongoing education to up skill local practitioners and trainees. This team approach has improved the services and outcomes for patients on non-dialysis pathways but also those on a dialysis pathway as an unintended ripple effect with different approaches to symptom control.

The role of the supportive care nurse in this model is critical to the success of this model promoting a wider referral base especially from dialysis nurses and Allied Health. The caring physician’s may not always be aware of the iceberg of symptoms that are very apparent to the dialysis staff that care for these patients during the long hours of dialysis.

A similar model is being set up in Western Australia linking into existing palliative care services if available.11

Options for certification in renal supportive care for nurses and allied health professionals and ongoing education in renal supportive care need to be explored with the Renal Society of Australasia (RSA).

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RENSAL SUPPORTIVE CARE AND THE PRIMARY CARE PHYSICIAN

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- General practitioner are important and should be involved in decision making and advanced care planning (ACP) for patients with advanced kidney disease.
Advanced kidney disease has a biphasic nature of life trajectory.
No treatment does not mean no dialysis for the patient with chronic kidney disease (CKD) – CKD care and terminal phase care.

For patients and their families undergoing renal supportive care, their primary care physician is an integral member of the multidisciplinary team. From a generic palliative care viewpoint, the Gold Standards Framework outlines the importance of the general practitioner in palliative care, the importance of enhancing knowledge and understanding of palliative care and underlines the need for effective communication, coordination and continuity of care. It emphasizes the importance of case identification, holistic assessment, care planning, individual case discussions and case management by a multidisciplinary team as well as family and carer’s assessment and support. These principles can be directly applied when evaluating the role of the primary care physician in renal supportive care.

Recent data from the AIHW indicates that for every new case of end-stage kidney disease (ESKD) treated with renal replacement therapy (RRT – dialysis or transplantation), there is one that is not, although the vast majority of those not treated are elderly. Furthermore, the rate of non-RRT treatment varies greatly with age, with RRT rates dropping progressively over the age of 65, with only about one-tenth of those aged 80 years or over receiving dialysis or transplant. The rising prevalence of progressive renal disease in older patients with higher levels of co-morbidities, highlights the importance of including general practitioners in the management of ESKD where supportive care is considered most appropriate. As well as raising awareness of this patient group, and help in the identification of these patients within the primary care setting, it is equally important to provide easily accessible information on the renal-specific palliation needs of these patients.

The life trajectory of ESKD is often one of relative preserved functional status until late in the course of the illness, which is characterized by a rapid decline toward death. This has clinical implications in delivery of care, with initial focus on CKD management – preventing progression of disease and management of CKD related complications, in the largely asymptomatic apparently well patient, followed by the more rapid phase of terminal uraemia, during which patients may experience a wide range of symptoms.

Communication with and from the patient’s renal unit is vital. Of prime importance is to check what if any conversations and decisions about ACP have been made. This is particularly important for the patient who wishes to die at home, a situation where the general practitioner becomes central to the coordination of care. A number of resources exist to assist the GP in ACP discussions with patients and their families. Though there are legal differences in ACP from state to state, and country to country, The RACGP Guidelines for ACP contains a wide range of useful resources.

Resources to guide renal supportive care of the patient with advanced CKD

A. CKD management issues

The main focus in the early phase is the care of the CKD patient to reduce progression of disease and manage other complications – a no-dialysis option does not mean a no-treatment option. Actively treating the metabolic complications of advanced CKD can improve quality of life and reduce the symptom burden. The principles of managing anaemia with erythropoietin stimulating agents, CKD-MBD (phosphate binders, active Vitamin D), hypertension, fluid management and specific considerations regarding drug dosing in advanced CKD, contained in the Chronic Kidney Disease Management in General Practice.

B. Care of terminal phase of ESKD

Patients with advanced CKD can look relatively well until the more advanced stages of uraemia. They can experience the whole range of symptoms more commonly associated with oncology palliation. These include pain, restless legs, nausea and vomiting, retained secretions, dyspnoea, and terminal agitation. Treatment options and doses are often constrained in patients with very low levels of renal function.

For the patient who chooses to die at home, the GP will play a pivotal role in coordinating the medical care of the patient, working closely with the local palliative care service. Many of the palliative care units are able to visit patients at home and liaise with the patient’s GP regarding symptom control. A number of specific resources such as the KHA booklet Management of CKD, Guides to End of Life drugs for End Stage renal disease, (LCP National Renal Steering Committee) or similar are available to help with specific decisions.

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RESEARCH ISSUES IN ELDERLY PATIENTS: GAPS IN KNOWLEDGE AND SUGGESTED DIRECTIONS

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Concentration of research is recommended in the following areas:

• Prospective studies of the appropriateness, relevance, timing and sustainability of dialysis in elderly patients.

• Health-related quality of life (HRQoL) in older patients choosing not to dialyse and in those choosing to dialyse with comparison to a matched population without renal disease.

• Methods of communication of prognosis and factors affecting decision-making.

• Models of care – comparative studies to delineate how best to deliver renal supportive care.

• Treatment preferences amongst indigenous patients.

• Symptom control, focussing on those areas specific to the needs of renal patients.

There has been an increase of over 400% in the number of elderly and very elderly patients on dialysis in Australia and New Zealand (NZ) over the past two decades.3 This rapid increase has generated considerable debate resulting in wide variation in attitude towards referral and acceptance of elderly patients for dialysis.2,4 One major reason for this is that there is uncertainty about the outcome from dialysis treatment in this population.5 If conservative management is shown to be effective and valid option with similar outcomes to dialysis, then this can be appropriately discussed with the individual and their family/whanau (Maori – extended family) without this being considered as rationing, or limiting individual and immediate family. Dialysis may prolong life, however it also ‘remains an aggressive tertiary intervention that may challenge the priorities and attitudes of older patients in particular’.6 Dialysis also has hazards, and in some patients it will shorten life. This is a particularly critical issue in the older age group. The patient’s preference and quality of life are central issues.6 It has also been found that both dialysis patients and their partners are overwhelmed by the impact of dialysis on their lives.6 In a patient survey conducted by Davison and colleagues,9 60.7% of patients regretted the decision to start dialysis. However, if patients opt for conservative therapy (no dialysis) it is unknown how much life expectancy, as well as the quality of life, is actually altered. It is possible that the intervention of dialysis may actually make the quality of life worse, particularly in the presence of significant comorbidity. Currently, there is a small amount of retrospective data only,8 but no prospective scientific data to support either point of view to help clinicians, their patients and family/whanau to make a decision.

A study from a large London dialysis centre looked at outcomes between two groups of older patients, one group that opted for dialysis therapy and the other that chose maximal conservative care. Those opting for conservative care were older (mean age 82 years vs 76 years). Although the dialysis group survived for a longer period (mean 2 years), the majority in the conservative group survived for
over 13 months with substantially lower hospital days (16 days per patient per year) and the majority in this group died at home.\textsuperscript{10} The dialysis patients were dialysed in a hospital centre that meant they averaged 173 days per patient per year at the hospital. This study did not record any quality of life assessment, data related to patient satisfaction, cost-effectiveness or the socioeconomic impact of the hospital-based treatment.\textsuperscript{10}

1 In a thematic analysis of the literature Morton and colleagues demonstrated that awareness of factors associated with decision-making related to the management of chronic kidney disease (CKD) can provide health professionals with evidence on how best to deliver education programmes for patients and their family, as well as enhancing the patient and their family’s capacity to share in that decision-making process.\textsuperscript{11} They identified four themes – confronting mortality (life/death, burden on family, state of limbo), lack of choice (options not always discussed), knowledge of options, and weighing the alternatives.\textsuperscript{11} These are important issues that future research with respect to both active RRT and renal supportive care need to address.

2 In addition to the impact of dialysis treatment on the individual, there is a significant health-economic implication for Australia and NZ, with the approximate cost of dialysis per individual at about $65 000 to $80 000 per year. This equates to around $56 million per year in NZ, and $370 million per year in Australia for those on dialysis over the age of 65 years.\textsuperscript{12} This cost does not include the cost of hospitalization and the impact of any other associated comorbidity that is frequently present in the elderly and may be exacerbated by end-stage kidney disease (ESKD) and/or its treatment. Although the crude cost for RRT can currently be estimated, there is little information about patient-experienced benefits to the individuals beyond survival.

3 There are gaps in our current knowledge about the cost of a well-staffed multidisciplinary renal supportive care programme which also needs to be researched with outcomes measured in quality adjusted life years to match data being acquired for dialysis programmes.

The determinants of successful dialysis in the elderly will be multifactorial including the degree of autonomy or control related to managing dialysis (home care vs satellite or in centre based care), and the many socioeconomic factors related to the management of a chronic disease superimposed upon the aging process.

It is vital for future health-care delivery of RRT in those aged ≥65 years in Australia and NZ that reliable data are obtained. In NZ in 2008, there were 154 new patients over 65 years commencing dialysis. This is a rate of 397 per million compared with the overall rate of new patients at 109 per million.\textsuperscript{1} Recent estimates from the Australian Institute of Health and Welfare suggest dialysis rates fall from around 90% in the younger population to about 10% in those aged ≥80 years.\textsuperscript{11} It is therefore important to have accurate data upon which to base priority decisions regarding health funding and outcomes.

4 Dialysis survival data are collected through the ANZDATA registry\textsuperscript{1} but HRQoL information is not collected. The data with respect to outcomes includes only those individuals who have survived the first 90 days on dialysis and does not include data on those who opt out of dialysis. Crucially what remains unknown is: (i) knowledge about HRQoL at the time of commencing dialysis among the elderly, and (ii) knowledge about HRQoL and perceptions/experiences across the entire trajectory of dialysis – from the decision to commence dialysis (or not) until death. Withdrawal from therapy now contributes up to 30% of the deaths for individuals on RRT.\textsuperscript{1} Decision-making should, and clearly does, involve the patients and their carers, along with health service providers. However, there is currently a dearth of evidence related to such decision-making in elderly dialysis patients.

There is virtually no published HRQoL data on the elderly Australian and NZ patient on dialysis. The limited data available from overseas are not relevant to clinical practice in Australia and NZ due to marked differences in how health care is delivered. Dialysis overseas is predominately privately funded with financial implications having a substantial impact on decision-making (both physician and patient/family). For example, home-based dialysis (peritoneal dialysis or haemodialysis) accounts for less 5% of dialysis in the USA or Europe. This, plus obvious cultural differences makes it imperative that there is good Australian and NZ data for health-care delivery relevant to both countries.

Dialysis buys a period of survival for most with ESKD. HRQoL may be the best measure of the value of this dialysis. There is thus a need to obtain Australian and NZ-specific HRQoL data about this cohort of older patients with CKD, considering RRT, including those who elect not to enter the dialysis programme. This needs to be compared with available data addressing HRQoL in the older population of Australia and NZ (not on dialysis).\textsuperscript{14,15} Reliable HRQoL data will be helpful to an older patient and his/her family, whanau contemplating RRT and to health-care providers to assess the usefulness of dialysis treatment programmes in a comprehensive manner. This type of data can provide a benchmark against which outcomes of future interventions may be measured.

In addition, further research could focus on other gaps in our knowledge such as:

1 How to best communicate prognosis (for example using graphs, quantitative risk charts, or comparison with cancers)

2 How to best deliver renal supportive care – that is, comparison of models of care

3 The exploration of carer experiences of a family member treated within a renal supportive care programme

4 The treatment preferences of indigenous patients and their family
5 Better studies on therapies for symptom control specific to the needs of renal patients.

**Current research**

Dialysis and supportive care for the elderly is an area that is attracting interest with a number of studies already initiated. These include:

1. PINOT – **Patient IN**formation about **Options for Treatment**. (national follow-up study): CIs R Morton, N Gray, P Kerr, P Snelling, A Webster, K Howard, K McGeechan. Trial register number: NCT01298115.

2. End-of-life care in end stage renal disease: Integration of an advance care planning process. CI S Davison (Canada) and Cochrane Renal Group. Trial register number: ACTRN1261000782033.


4. A Representational intervention to promote preparation for end-of-life decision making (SPIRIT). CI Mi-Kyung Song (Chapel Hill, USA). Trial register number: NCT01259011.

**Unregistered studies**

1. CONSIDER – **CO**nsiderations of **N**ephrologists when **S**uggesting **D**ialysis in **E**lderly patients with **R**enal Failure. CIs C Foote, R Morton, M Jardine, M Kimman, K Howard, A Cass. A discrete choice analysis survey assessing nephrologist preferences for dialysis recommendation in elderly patients with varying comorbid conditions.

2. Pre-dialysis options discussion, prognosis and conservative care: A Pilot Project. CI M Germain (Springfield, USA). A multi-attribute survey study in pre-dialysis patients 75 years and older with CKD stage 4 or 5.

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**MANAGEMENT GUIDELINES FOR PATIENTS CHOOSING THE RENAL SUPPORTIVE CARE PATHWAY: INFORMATION AND WEB-BASED TREATMENT PROTOCOLS AVAILABLE TO ALL**

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- Available guidelines fall into two categories – medication guides and service provision guides.
- Few guidelines exist for the management of patients choosing to not have dialysis apart from those covering end-of-life (EOL) management and general ones for the management of chronic kidney disease.
- Most guidelines are only based on low level evidence, relying on expert opinion or current practice. This limits their usage when advising on matters such as trials of dialysis and caution should be applied when discussing these matters. More data are needed before firmer recommendations can be made.
- Units in Australia and New Zealand should consider maintaining registers of ‘at risk’ patients to allow greater input into symptom management and EOL support.
CARL, KDIGO, the Renal Association and other groups around the world produce guidelines for nephrologists to follow when caring for their patients. These include areas such as biochemical targets, access guidelines and dialysis monitoring guidelines. Many of these may be inappropriate for those choosing the non-dialysis pathway where quality of life (QOL) is often the dominant issue in management. In this article, the availability of guidelines for renal supportive care (RSC) patients was examined and the level of evidence for any recommendations made in available literature. The search strategy was to look at easily available, web-based guidelines from nationally accepted groups where English is the dominant language.

**What is available?**
Web-based guidelines fall into two categories –
- those dealing with specific clinical management issues such as pain, nausea, etc.
- those dealing with service needs and provision.

Few web-based protocols for management of symptoms are available, though individual hospitals may have intraweb-based protocols. This may be at least partially due to different prescriber limitations and formulary availability of medications in different centres leading to each group developing their own protocols and guidelines.

**CLINICAL GUIDELINES**

1. **Targets**
No specific guidelines exist for the management of areas such as calcium/phosphate balance, hyperparathyroidism, blood pressure control and anaemia in patients choosing not to dialyse and most doctors aim to meet the same targets as for patients with chronic kidney disease (CKD) still planning on dialysis (CARL, KDIGO guidelines). In the conservative pathway, these need to be balanced against QOL and it may therefore be appropriate to have different targets which will alter as disease advances. This is a potential area for collaborative research to produce guidelines for management.

2. **Trials of dialysis**
It is of note that most available guidelines, apart from a patient information section from Edinburgh Royal Infirmary (ERI),¹ suggest that a trial of dialysis may be appropriate for some patients. The ERI site states the reasons why it is not thought to be appropriate.¹ Neither position, either for or against trials of dialysis, is based on high level evidence and does potentially suggest an area requiring research, that is loss of residual function following initiation of dialysis. This also highlights potential areas of conflict in discussing palliative care in renal failure without higher level evidence to back up those discussions.

3. **Medication**
The Liverpool Care Pathway (LCP)² is perhaps the most widely known set of guidelines available. These guidelines are not aimed at chronic management of RSC patients but are specifically targeted at EOL. They are available via The Renal Association website. A working group of renal and palliative care physicians was formed to produce a renal-adapted form of the LCP.

Whilst these guidelines are targeted towards care at the terminal stage of disease, they do include a useful analgesic ladder. The guidelines in general are produced as easy to follow flow charts and cover symptoms and signs including constipation, pruritus, pain and dyspnoea. Some guidelines such as those covering fever, would not be appropriate in most RSC patients as the only recommendation is for the use of paracetamol. In an actively managed RSC patient not yet approaching EOL, antibiotics are more likely to be the management choice.

The St George’s Hospital web-site³ also includes a section on palliative care drug guidelines. This has been adapted from the Yorkshire Palliative Medicine Guidelines (2006) and gives comprehensive information about drug usage including dose and timing adjustments, elimination and other helpful comments to guide the prescriber. There is also a useful powerpoint presentation from Dr F Brennan covering symptoms and the evidence for various treatments. In particular, this is helpful for conditions such as Restless Legs Syndrome and pruritis which are often very difficult to manage.

In North America, the Mid-Atlantic Renal Coalition (MARC) and Kidney End of Life Coalition have developed a clinical algorithm to treat pain in dialysis patients. Whilst these clinical guidelines were developed to aid management of pain specifically in dialysis patients, they provide a useful review of suitable analgesics and an analgesic ladder specifically adapted for patients with renal failure. Nociceptive and neuropathic pain is covered as well as the management of analgesia-associated side effects. Further dosage adjustments may be necessary for certain medications (e.g. Gabapentin) in patients choosing not to dialyse.

**ETHICAL AND SERVICE GUIDELINES**

Some guidelines deal with how to manage discussions around the question of dialysing, others concern themselves with what is necessary for adequate service provision.

In Australia and New Zealand, the CARL Guidelines include two sections of note – ‘Ethical Considerations’ and ‘Quality of Life’. The suggestions in the section ‘Ethical Considerations’, dealing with acceptance onto dialysis, are based on level III and IV evidence and are not protocols for management of people choosing a supportive care pathway. This paper does discuss the concept of ‘benefit’ to the patient. Trials of dialysis are also discussed where there is uncertainty about potential benefit from dialysis. It does not discuss the potential disadvantages of such a trial and what evidence may be available to support this approach.

The section on ‘Quality of Life’ again deals with recommendations at a level III or IV only – no recommendations...
based on higher level evidence are possible. It recommends the use of a multidisciplinary team in discussing the potential effects of dialysis on QOL, including not just physical effects but also social and family effects. It recommends that not just age must be used as a predictor of poor QOL but also physical and mental functioning. This is important as some studies suggest that the physical effects of deteriorating health are less important to satisfaction with life in older patients vs younger patients.

1. Service Provision
The Canadian Society of Nephrology published guidelines for the management of CKD in 2008. This document does not include web-based protocols for management of patient symptoms but gives guidelines on how a programme should function. There is also a published article based on these guidelines on the management of CKD including a section on conservative management stating the need for comprehensive, proactive management.

The following summarizes the areas covered in the document –

**Guidelines 3.3–3.6 Comprehensive Conservative Management.**

All are grade D, opinion guidelines
- This section, written in 2008, includes discussion on
  - (i) Time-limited trials of dialysis
  - (ii) Prognostic tools
  - (iii) Membership of an interdisciplinary team
  - (iv) Need for training
  - (v) Development of care plans
  - (vi) Advance Care Planning
  - (vii) Components of comprehensive conservative management – including symptom management, psychological care and spiritual care.
  - (viii) Care of the imminently dying patients – availability of co-ordinated EOL care.

These articles are potentially helpful when assessing personnel and material needs when initiating a conservative care programme. There is a special emphasis on the need for a multi-disciplinary team to care for patients on the Supportive care pathway.

2. Initiation, withholding and withdrawal of dialysis
The Renal Physicians Association (RPA) and the UK Renal Association both have guidelines around initiation, withholding and withdrawal of dialysis. In the USA, the RPA published Clinical Practice Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis in 2010, jointly with the American Society of Nephrologists. These comprehensive guidelines present a position on aspects such as prognostication, conflict resolution and palliative care. They are presented as recommendations with accompanying explanations and references. These would be useful as a base for setting out guidelines for
- Identifying patients
- Estimating prognosis
- Appropriate care pathways
- Interning and withdrawing of dialysis care
- Provision of palliative care
- Communication

The UK guidelines are ‘Planning, Initiating and Withdrawal of Renal Replacement Therapy’. The evidence for these recommendations has been assessed using the modified GRADE system which classifies expert recommendations (1 Strong, 2 Weak) and quality or level of evidence (A – High to D – very low).

**Guidelines 6.1–6.5** deal with EOL, conservative management and withdrawal of dialysis. They recommend
- a register of patients identified with EOL needs including those on a conservative management plan, on dialysis or withdrawing from dialysis
- individualized discussions between patients, nephrologists and patients
- Advance care planning to facilitate communication
- Consideration of the use of the LCP for dying patients
- Participation in audits about EOL

In the UK, the Renal National Service Framework from the NHS recommends that all units have a register of patients meeting criteria likely to be associated with clinical decline, likely to be approaching the EOL. These people can be identified by all members of the multi-disciplinary team and this identification leads to increased input, e.g. social work, ACPs, greater focus on symptoms. This approach could be considered for institution in Australia and New Zealand as a way of focussing attention on this group, collecting data for a better estimate of the numbers and aiding support and input into these patients’ care as they approach EOL.

3. Conflict Resolution
Conflict resolution is a difficult area to deal with and has been a reason for some patients being initiated on dialysis when it may not have been the most appropriate management choice.

**NSW Department of Health** published a report in 2010 – Conflict Resolution in End of Life Settings (CRELS). This report includes discussion of the problems encountered when clinicians from other specialities prognosticate on a condition, misconceptions about a ‘Not for Resuscitation’ order and ongoing management, unrealistic expectations of modern medicine as well as ethical and legal issues in EOL decisions. It also includes a flow chart aimed at resolving EOL conflicts in a patient who has lost decision-making capability as well as guidelines for formulation of and End of Life Care plan. This helpful review can assist in formulating local guidelines which need to take account different legal positions in different countries, states and territories (see section 19). We stress the importance of ‘second’ and other medical and ethical opinions in difficult cases when conflict arises.

**SUMMARY**
Many guidelines exist around the world around RSC but most are based on low level evidence. Analgesic use is probably the best referenced and available but many other areas
need ongoing research before guidelines supported by higher level evidence can be formulated.

OTHER GUIDELINES

1. KDIGO
No recommendations
KDIGO has recently begun work to look at the formulation of guidelines in this area.

2. KDOQI
1.3 Timing of therapy:
When patients reach stage 5 CKD (estimated GFR < 15 mL/min per 1.73 m²), nephrologists should evaluate the benefits, risks, and disadvantages of beginning kidney replacement therapy. Particular clinical considerations and certain characteristic complications of kidney failure may prompt initiation of therapy before stage 5. (B)

3. European Best Practice Guidelines
Guideline D. ‘Conservative management should be aimed at promptly initiating therapy before stage 5.’ (Evidence level C)

Guideline E. This guidelines discusses when dialysis should be initiated and ensuring that it is not instituted when eGFR falls below 6 but between 8–10 mL/min per 1.73 m². It does not discuss management of patients in whom dialysis is not to be instituted.

4. CMAJ. [Cited 15 May 2013.] Available from URL: http://www.cmaj.ca/cgi/content/full/179/11/1154/DC1

LEGAL ISSUES CONCERNING WITHHOLDING AND WITHDRAWAL OF DIALYSIS

Cameron Stewart and Frank Brennan, 1 Centre for Health Governance, Law & Ethics, Sydney Law School, University of Sydney, Sydney, and 2Departments of Renal Medicine and Palliative Medicine, St George Hospital, Kogarah, New South Wales, Australia

- A doctor incurs no civil or criminal liability if, on the basis of a refusal to commence or continue dialysis, the doctor does not give that treatment. To go ahead and give treatment to a patient who has refused consent, constitutes a battery.

- If the actions of a nephrologist are reasonable in withholding dialysis or withdrawing from dialysis then it is highly unlikely that a negligence action would be successful.

- The law does not obligate a nephrologist to provide treatment that they believe is of no benefit to the patient, but best practice requires that the nephrologist communicate with the substitute decision-makers regarding the patient’s best interests.

- Withholding or withdrawing dialysis is not euthanasia. Equally it does not constitute Physician Assisted Suicide.

- If a patient is competent the patient makes the decision whether or not to consent to dialysis. The family cannot insist on dialysis when a patient refuses.

- If the patient is incompetent and there is a dispute between the surrogate decision makers and clinical team are in dispute about treatment, some simple preliminary steps may be taken, including seeking a second opinion. Ultimately, disputes can be resolved by the Supreme Court or guardianship authority.

A substantial body of law has developed over centuries establishing clear legal principles that have a direct relevance to the practice of Nephrology, including decisions made to withhold or withdraw dialysis. Firstly, and as a foundation principle, the law neither seeks nor expects perfection from doctors. What it does expect is that doctors, including nephrologists, act reasonably in all aspects of their professional practice.

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4. CMAJ. [Cited 15 May 2013.] Available from URL: http://www.cmaj.ca/cgi/content/full/179/11/1154/DC1


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CAPACITY

Competent patients have a right to make decisions regarding their treatment. In essence, competency requires the following:
1. The person understands what is being said to them.
2. The person retains that information.
3. The person exercises reason to reach a conclusion.

The test for patient capacity was set out the case of Re MB (Medical Treatment) [1997] 2 FLR 426 at [30]:

A person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment. That inability to make a decision will occur when:
   a. the patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
   b. the patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision.

INFORMED CONSENT

For competent patients, the law expects that:
   a. Consent must be voluntary and made without undue influence.
   b. Consent should also be informed. This means that the patient should be told about the material risk of having or not having the treatment. Material risks are:
      i. Objective risks which a nephrologist would always tell a patient; and
      ii. Subjective risks, about which the patient has expressed some concern, such as by asking questions or through their presentation.

REFUSAL OF CONSENT

A competent patient has the legal right to refuse medical treatment, including dialysis. That right exists, even if the treatment is life-sustaining. If a patient with chronic kidney disease (CKD) makes a decision to refuse the commencement of or continuation with dialysis, they have a legal right to do so.

Importantly, a doctor incurs no civil or criminal liability if, on the basis of a refusal to commence or continue dialysis, the doctor does not give that treatment. To go ahead and give treatment to a patient who has refused consent, constitutes a battery.

ADVANCE REFUSALS OF DIALYSIS

A patient can make a decision in advance of their mental incapacity to refuse dialysis. This is known as an advance directive. Advance directives are decisions made by patients about what medical treatments they would like in the future if, at some point, they cannot make decisions for themselves. Advance directives are recognized at common law in both Australia and New Zealand.

Case study

In Hunter and New England Area Health Service v A [2009] NSWSC 761. Mr A was a Jehovah’s Witness who had completed an advance directive in which he had indicated his wish not to be given dialysis. In June 2009 A was admitted to the hospital suffering septic shock. His kidneys failed and he was being kept alive on a ventilator and dialysis machine. McDougall J upheld A’s right to refuse treatment and found that even though there was no express provisions for advance directives in Guardianship Act 1987 (NSW), s 33 of the Act recognized the importance of the patient’s previously express decisions regarding treatment.

All Australian states and territories (apart from NSW and Tasmania) also have created statutory advance care directives. In New Zealand, advance directives are based on common law but are recognized in the Code of Health and Disability Services Consumer’s Rights at 7(5). These laws are set out in Table 1.

SUBSTITUTE DECISION-MAKING FOR INCAPACITATED PATIENTS

It is important to note from the outset that common law has never recognized the rights of the ‘next of kin’ to consent to medical treatment for adult incompetent patients. Family members only have such powers when they have been legally appointed as a substitute decision-maker.

In Australia, each jurisdiction has its own guardianship law which creates different types of substitute decision-makers who can give consent to treatment. Substitute decision-makers generally take three forms: guardians (appointed by the guardianship authorities), enduring attorneys (appointed by the patient whilst competent and referred
to as ‘enduring guardians’ or ‘medical agents’ in some jurisdictions, and persons responsible (ordinarily close friends or relatives who can make decisions for the patient, in the absence of any formal appointment). These multilayered approaches are meant to ensure that someone will always be available to make treatment decisions for an incompetent patient. Unfortunately, these laws do not always clearly provide the substitute decision-makers with power to consent to treatment limitation. A summary table of the legislation is contained in Table 2.

In New Zealand, patients can appoint enduring powers of attorney prior to their incapacity. New Zealand law allows for the court to appoint a welfare guardian. Both these decision-makers are empowered to make personal and welfare decisions including treatment decisions. Neither can refuse treatment when a treatment team believes the treatment to be standard medical treatment intended to save the person’s life or prevent serious damage to the person’s health. Apart from enduring powers of attorney and welfare guardians, relatives do not have general a power to consent to treatment in New Zealand. However the courts have strongly indicated that relatives should be consulted when health care professionals are making assessments of the patient’s best interests.

The ultimate substitute decision-maker is the court as parens patriae. All Australian Supreme Courts and the New Zealand High Court have this power and disputes between parties regarding the patient’s best interests are often resolved there. In Australia, each state and territory also has guardianship tribunals which deal with these matters.

**Table 1** Advance care directives legislation in Australia and New Zealand

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Legislative scheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td><strong>Medical Treatment (Health Directions) Act 2006</strong>: A health direction can be made to refuse treatment of require withdrawal of treatment generally or of any particular kind of the treatment.</td>
</tr>
<tr>
<td>NT</td>
<td><strong>Natural Death Act 1988</strong>: A direction only becomes effective when the patient is suffering from a ‘terminal illness,’ which is defined as an illness, injury or degeneration leading to an imminent death and from which there is no reasonable prospect of temporary or permanent recovery: s 3.</td>
</tr>
<tr>
<td>Qld</td>
<td><strong>Powers of Attorney Act 1998</strong>: A directive only becomes operative when: (a) the principal is terminally ill and is not expected to live more than a year, or is in a persistent vegetative state, or is permanently unconscious, or has a severe illness with no reasonable prospect of being able to live without the continued application of life-sustaining measures; and (b) (if the direction concerns artificial hydration or nutrition) the life sustaining measure would be inconsistent with good medical practice; and (c) the patient has no reasonable prospect of regaining capacity for health matters.</td>
</tr>
<tr>
<td>SA</td>
<td><strong>Consent to Medical Treatment and Palliative Care Act 1995</strong>: A direction only becomes operative when the patient is in a terminal phase of a terminal illness, and is no longer competent. NB: There is a new Advance Care Directives Bill 2012 being considered by parliament at the time of writing.</td>
</tr>
<tr>
<td>Vic.</td>
<td><strong>Medical Treatment Act 1988</strong>: A patient can only refuse treatment in a certificate when the treatment is related to a ‘current condition.’ Palliative care cannot be refused and this is defined to include the ‘reasonable provision of food and water.’</td>
</tr>
<tr>
<td>WA</td>
<td><strong>Guardianship and Administration Act 1990</strong>: A directive will not operate if circumstances have arisen that the patient had not anticipated and would cause a reasonable person to change their mind about the treatment decision.</td>
</tr>
<tr>
<td>New Zealand</td>
<td><strong>Code of Health and Disability Services Consumer’s Rights Act 2003</strong> (c) the patient has no reasonable prospect of regaining capacity for health matters.</td>
</tr>
</tbody>
</table>

**DO SUBSTITUTE DECISION-MAKERS HAVE A LEGAL RIGHT TO DEMAND DIALYSIS?**

In cases where a patient is competent, the decision regarding the administration of dialysis must be made by the patient. If it is shown that substitute decision-makers have exerted undue influence on the patient and forced them to consent or refuse dialysis, that decision may be held to be invalid.

In cases where the patient is incompetent and has made no advance directive, substitute decision-makers do not have a legal right to demand dialysis which is not in the patient’s best interests. In such cases it is best practice to have sought second opinions relating to the patient’s diagnosis and prognosis, and to have attempted to mediate with the substitute decision-makers to try and reach a consensus. If arguments arise between substitute decision-makers and clinicians that cannot be resolved, both the clinicians and/or the substitute decision-makers have the right to seek orders from a court or tribunal.

**CAN I BE SUED FOR WITHHOLDING OR WITHDRAWING DIALYSIS FROM A PATIENT?**

Medical negligence arises when it can be shown that a doctor’s behaviour fell below a standard of care, and that breach...
Table 2 Summary of substitute decision-makers who may consent to the withhold or withdrawal of dialysis

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Comments – can substitute decision-makers consent to dialysis being withheld or withdrawn?</th>
</tr>
</thead>
</table>
| ACT          | • Guardians are given powers to consent to medical procedures but not an express power to refuse treatment: Guardianship and Management of Property Act 1991, s 7. The position is unclear but arguably similar to NSW where guardians can refuse treatment.  
  • Enduring attorneys over healthcare can make decisions to withhold or withdraw medical treatment: Powers of Attorney Act 2006, s 12.  
  • Health attorneys (domestic partners, carers or close friends and relatives) may consent to treatment but should they refuse to consent the matter must be referred to the Public Advocate: Guardianship and Management of Property Act 1991, s 32H.  
  • This presumably means that refusal must be reviewed by the Public Advocate, who then makes the decision regarding treatment, but this review would only be triggered when the treatment team wishes for the treatment to commence/continue and where the health attorney disagrees. If both the treating team and attorney agree that treatment should be limited it seems unlikely that the Public Advocate would become involved.  
  • In cases of conflict, resort should be had to ACAT or the Supreme Court to seek advice  
| NSW          | • Guardians can refuse treatment if they have been granted a plenary power or a healthcare function: FI v Public Guardian (2008) NSWADTAP 263  
  • Enduring Guardians may not be able to refuse treatment unless they have been granted a plenary power or a healthcare function a specific power to do so in the instrument.  
  • Persons responsible are also unlikely to be able to refuse treatment as they must consent to treatments which promote and maintain health and wellbeing: Guardianship Act 1987. However there is conflict on this point: HH v Hi and Protective Commissioner (2009) NSWADTAP 41.  
  • If the treatment team and substitute decision-makers agree to withhold/withdraw dialysis in the patient’s best interests then arguably there are no legal barriers to doing so. In cases of conflict, resort should be had to the Guardianship Tribunal or Supreme Court to seek advice.  
| NT           | • Guardians are given plenary powers as if they were the parent of the patient and may consent to treatment in the patient's best interests: Adult Guardianship Act s 17. Arguably this includes end-of-life functions.  
  • The Northern Territory does not provide for enduring powers of attorney over healthcare or person responsible legislation.  
  • Decisions to limit treatment would be made by the treatment team based on an assessment of the patient’s best interests. That assessment should ordinarily include consultation with the patient's family/friends: Inquest into the death of Paulo Melo (2008) NTMC 080; Melo v Superintendent of Royal Darwin Hospital [2007] NTSC 71  
| Qld          | • Guardians are given clear power to withhold and withdrawal life sustaining treatments: Guardianship & Administration Act 2000, Sch 2, s 5  
  • Enduring attorneys over healthcare can make decisions to withhold or withdraw medical treatment: Powers of Attorney Act 1998, Sch 2.  
  • Statutory health attorneys (spouse, carer, close friend or relation) also have the power to refuse treatment: Powers of Attorney Act 1998, Sch 2.  
  • Healthcare professionals must seek consent to limitation of a ‘life sustaining measure’. A life-sustaining measure is health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. This probably includes dialysis.  
  • A decision by substitute decision-makers to withdraw or withhold treatment will not be effective unless continued treatment is inconsistent with good medical practice.  
  • In cases of conflict, the Public Advocate automatically is appointed as the substitute decision-maker. Alternatively, orders can be sought from the QCAT or Supreme Court.  
| SA           | • Guardians are given plenary powers that a guardian would have at law or in equity: Guardianship and Administration Act 1993, s31. Arguably this should include powers to refuse treatment.  
  • Medical attorneys can also be appointed with powers to make decision s about medical treatment which appear to include power to refuse treatment: Consent to Medical Treatment and Palliative Care Act 1995, s 8. NB: There is a new Advance Care Directives Bill 2012 being considered by parliament at the time of writing. Powers must be exercised (a) in accordance with any lawful conditions and directions contained in the medical power of attorney; and  
  (b) if the grantor of the power has also given an anticipatory direction – consistently with the direction, and subject to those requirements, in what the agent genuinely believes to be the best interests of the grantor.  
  • Medical attorneys cannot refuse natural administration of food and water, palliative care or treatment which would return the grantor to capacity: s 8.  
  • Enduring guardians can also be appointed. They are bound:  
    (a) to exercise powers at law or in equity of a guardian if the person who makes the appointment subsequently becomes mentally incapacitated; and  
    (b) in that event, to consent or refuse consent to the medical or dental treatment of the person, except where the person has a medical agent available and willing to act in the matter.  
  • Persons responsible [including family members] can give consent to treatment in the patient’s best interests: Guardianship and Administration Act 1993, s 59. A doctor can carry out treatment against the wishes of a person responsible if they believe the treatment to be in the patient’s best interests: s 42 L  
  • Healthcare professionals responsible for the treatment or care of a patient in the terminal phase of a terminal illness, is, in the absence of an express direction by the patient or the patient’s representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state: Consent to Medical Treatment and Palliative Care Act 1995 s 17(2).  
  • This indicates that consent should be sought to the treatment limitation from the patient or their representative.  

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ANZSN Renal Supportive Care Guidelines 2013
caused the patient harm. In any action in negligence, the court would require that the patient prove, on the balance of probabilities, that:

- the nephrologist owed a duty of care to the patient. The nature of a doctor-patient relationship would automatically satisfy this criteria;
- the nephrologist breached that duty to the patient. Here the court will look to see if the nephrologist acted in accordance competently. This is assessed by reference to peer professional opinion. If it can be shown that other nephrologists would have also withheld or withdrawn the treatment then the standard of care has been satisfied; and
- the breach caused damage or harm to the plaintiff.

If the actions of a nephrologist in withholding dialysis or withdrawing from dialysis are supported by peer professional opinion, then it is highly unlikely that a successful action in negligence would occur.

### IS WITHDRAWING A PATIENT FROM DIALYSIS EUTHANASIA?

No. Euthanasia is defined as a deliberate act with the intention to end a person’s life in the context of a serious illness. The withholding of a treatment or the withdrawing from a treatment are considered entirely valid both ethically and legally – as well as medically – where the burden of the treatment is outweighed by the benefit to the patient. Neither the withholding of nor withdrawing from dialysis is euthanasia.

### IS WITHDRAWAL FROM DIALYSIS PHYSICIAN-ASSISTED SUICIDE?

No physician-assisted suicide (PAS) is entirely different to the ceasing of a treatment. PAS is a positive act done by a patient to cease life and where a physician has assisted in its execution
(usually by prescribing medications used in the suicide). The withdrawing of treatment, including dialysis, is an entirely different act where the death, when it results is due to the underlying disease and not due to the action taken by the patient.

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EDUCATIONAL NEEDS IN SUPPORTIVE AND END-OF-LIFE CARE

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- With variable availability of renal supportive care (RSC) programmes available throughout Australia and New Zealand, there is a need for provision of training in this area to be available to all medical and paramedical staff
- Online resources may be a potential source of training material for staff and information for patients and families.
- The possibility of exchange programmes between renal medicine and palliative care should be explored as a way of enhancing education in both fields.
- The ANZSN and the ANZ Society of Palliative Care both have special interest groups in RSC. The potential for bringing these two groups together to facilitate cross-specialty training should be explored.

NEPHROLOGY TRAINEES AND NEPHROLOGISTS

The incidence of end-stage kidney disease (ESKD) in Australia and New Zealand is increasing (ANZDATA 2011). Patients with ESKD both on dialysis and conservative care pathways are sicker and more debilitated than in the past.1 Patients with chronic kidney disease (CKD) and ESKD are amongst the most symptomatic of any chronic disease group.2,3 With increasing evidence that patients with multiple co-morbidities may not benefit from dialysis,4–6 it is essential that nephrologists are trained in the conservative management of ESKD.

The current curricula for Australian and New Zealand Nephrology advanced trainees (http://www.rpctraining.com.au) recognizes this under learning objective 2.3.8 ‘plan and manage the non-dialysis pathway’.

THE SKILLS LISTED ARE

- Manage common ESKD problems – pruritus, fatigue, xerostomia, depression, constipation, insomnia, nausea, vomiting, dyspnoea and pain
- Adjust drug doses according to reduced GFR
- Liaise with allied health staff
- Describe reduced life expectancy to a patient with respect, empathy and dignity.

However with only a small number of conservative care clinics in Australia and New Zealand, trainees and nephrologists may receive very limited exposure to symptom control and conservative management. This has been the experience overseas, with a survey of nephrology trainees in the US revealing their training resulted in them feeling least prepared to manage a patient at the end of life.7

In order to provide adequate conservative care, nephrologists need to be confident in recognizing and managing symptoms related to ESKD, to be aware when to refer to palliative care, and be able to facilitate advance care directives. Current evidence suggests that pain in CKD is both under-recognized and under-treated.8,9 Nephrologists should be comfortable with end-of-life discussions and providing prognostic information to patients and care-givers.10

A submission has been made to the Renal SAC via the RACP to include training in RSC as a separate pathway i.e., in the same way as dialysis or transplants are covered. The RSA NZ has already incorporated RSC into its training pathway.

Opportunities to enhance skills in this area need to be provided. Attendance at educational forums such as ‘Kidney School’ and the ‘St George Hospital Renal Palliative Care Symposium’ need to be encouraged. Consideration should be given to mandating a component of palliative care education in nephrology training. Training should be provided to ensure that nephrologists are confident and skilled in all aspects of conservative care of a patient with ESKD. These training opportunities should be open to nephrologists at all levels of experience. Proposed mechanisms include:

1. An exchange program between Palliative Care Registrar and Renal Registrar’s advanced training, or Aged Care Registrar and Renal Registrar’s advanced training (currently available in the US)
2. Participation in the Liverpool Care Pathway (LCP) training sessions (available online, and through state palliative care centres and some hospitals, e.g. Fremantle Hospital WA, http://www.nursingtimes.net/online-nurse-training-courses/Liverpool-Care-Pathway-for-End-of-Life-Care, http://centreforpallcare.org/index.php/resources/end_of_life_care_pathways/)
3. Participation in an Advanced Care Planning program (see http://www.rpctraining.com.au/ for online and 1 day courses)
4. Short rotation through a unit that has a Renal Conservative Care management clinic
NURSING

It is essential that all renal caregivers are equipped with the skills to support patients who chose a conservative pathway, or elect to withdraw from dialysis. ESKD patients want more education on end-of-life issues and look to their health-care providers for information, with the majority looking to their nephrologist and nephrology nurse for this support.

Provision of ongoing education to renal nursing staff to enable them to provide ongoing nursing care, psychosocial and emotional support to patients is necessary to ensure that patients are receiving holistic care. Nursing staff role can vary between being a patient advocate, and/or a family supporter, as well as participating in ongoing disease management and patient education.

Nursing staff need to be equipped with the skills to participate in advanced care planning, in discussions regarding prognosis, end-of-life issues, in evaluating symptoms, and ideally in the use of palliative care assessment tools. Since quality of life (QOL) is subjective, it is paramount that nephrology nurses discuss QOL with patients to determine what would make a difference to them. Proposed mechanisms includes:

1. Training in the use of palliative care tools and palliative care pathways
2. Participation in advance care planning
3. Palliative care module as part of renal nurse training
4. Rotation in a palliative care ward or hospice (Possibly utilizing PEPA) or renal palliative care clinics
5. Support for renal staff for ongoing education in palliative care, e.g. palliative care diplomas, palliative care study days
6. Attendance at LCP education days
7. Access to online education for palliative care
8. Access to online guidelines for renal palliative care such as
   - Kidney end-of-life bibliography: http://www.kidneyeol.org/Files/PalliativeCareRefs.aspx
   - St George Hospital Renal Protocols Palliative care: http://stgrenal.med.unsw.edu.au/StGRenalWeb. ./. Palliative%20Care%20Section

ALLIED HEALTH

Effective delivery of high-quality palliative care requires good inter-professional team-working by skilled health and social care professionals. In order for a multidisciplinary approach to be effective, all team members must be cognizant of their own skills, as well as the skill set of other team members.

A study of occupational therapists working in palliative care found that the role of occupational therapy in palliative care is misunderstood; dying people, their carers, some health providers and the wider community did not understand the potential range of services that could be provided.

An audit of Australian tertiary teaching hospitals found that despite 65% of palliative patients presenting with a specific indication for physiotherapy, only 12.8% of these patients were receiving physiotherapy. This highlights the need for education of all disciplines involved in conservative management to ensure the optimum level of care is provided to the patient and their family.

Part of palliative management is the attention to ethical, psychosocial and spiritual issues related to end-of-life care. Social workers may be particularly helpful in these cases and have a recognized role in advance care planning. Patients’ preference for conservative care is influenced by the availability of subsidized transport and the ability to travel, both factors that may be addressed by social work.

Physiotherapy specific skills in symptom control management (e.g. TENS for pain relief, maintenance of mobility and physical function to optimize QOL and ease carer burden) can contribute significantly to the maintenance of independence and QOL of patients receiving palliative care.

Occupational therapists have the knowledge to assist people to participate in their chosen occupations, within the limits of their illness and to their satisfaction, by examining the symptoms caused by illness while determining barriers to self care, leisure and productive role. However a survey of occupational therapists felt they did not receive enough education in palliative care and as a result felt under-prepared to work in this field.

Dietitians have a role in ensuring adequate nutrition within the confines of a renal diet; assist in symptom control with digestive upsets, as well as supporting and educating family members about the many challenges of a renal diet.

As highlighted above, all members of the allied health team have important contributions to make to the care of a patient on the conservative pathway, but may not feel adequately trained. It is therefore essential that further education be provided both in undergraduate training, and in post-graduate setting. This may be provided by workshops, courses, in rotations through hospices or palliative care wards, as well as in Renal Units. Palliative care has been found to be a suitable setting for undergraduate interprofessional education.
PATIENTS AND FAMILIES

Patients and families should be involved in every step of the conservative care pathway. A survey of CKD stage 4 and 5 patients found they wanted greater education and support for families and a greater involvement of family in both care and decision-making. The same survey found that the majority of patients did not know what palliative care was, highlighting the current lack of patient education. Some patients may prefer to have advance care planning discussions with family or friends outside the patient-physician relationship; therefore it is imperative that family members are informed and supported through this process.

It is important that the individual and their family perceive a conservative care pathway is not withdrawal of treatment or care, rather an equally valid and fully supported option for the management of ESKD.

There are a number of online resources available to patients and their families, providing education and support, as well as literature currently available from palliative care teams.

Resources available include:

Supporting a Person Who Needs Palliative Care. A guide for family and friends. Peter Hudson PhD. Palliative Care Victoria
Commonwealth Respite and Carelink Centres: http://www.commcarelink.health.gov.au
Palliative Care Australia: http://www.palliativecare.org.au
LifeCircle (supports carers of people who wish to die at home). Ph. 1800 132 229: http://www.lifecircle.org.au
Caresearch (Palliative care knowledge network): http://www.caresearch.com.au
American association of kidney patients: http://www.aakp.org
Life Options: http://lifeoptions.org/

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CASE VIGNETTES

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CASE 1. THE DISTRESSED HEALTH CARE PROVIDER

Mr MF was a 72-year-old married father living independ-
ently with his wife.

Mr MF was admitted electively for non-operative correc-
tion of a known left renal artery stenosis. Previous investi-
gations reported two small kidneys with total obstruction of
the right renal artery and >60% obstruction of the left.
Recent health was compromised by multiple admissions to
 coronary care unit (CCU) with chest pain and acute pulmonary oedema (APO) despite recent plasty of a blocked coronary
graft, placed in 2002. An interventional radiologist accessed
the left renal artery. Unfortunately, the tip of the catheter
guide wire snapped off in the proximal part of the vessel,
totally occluding it. An interventional cardiologist was
unable to retrieve the remnant wire via a brachial approach.
The entry site at the right brachial artery puncture developed
an hematoma. The vascular surgeons opined that open revas-
cularization of the blocked renal artery was not an option.

Mr MF was anuric and the renal team were asked, for the
first time, to consult. The patient was noted to have excellent
insight into his medical problems and was keen to proceed
with a trial of dialysis. During the first haemodialysis treat-
ment, Mr MF lost consciousness for 15 s, requiring CPR. His
peripheral circulation returned spontaneously but, after the
event, the hematoma of the right arm was noted to be larger.
The vascular surgeons repaired a pseudoaneurysm in an
emergency procedure.

Mr MF remained olig/anuric and required ongoing dialy-
sis. He continued to experience chest pain, difficulty breath-
ing and ECG changes indicative of ischemia. During
discharge planning it emerged that Mr MF had a complex
social situation with a son who had a drug addiction, two
children in foster care and one grandchild in the custody of
Mr MF’s daughter who happened to live in the same unit
complex as her parents.

Mr MF was dialysis dependent and continued to experi-
ence chest pain due to demand ischemia at the time of his
discharge.

Mr MF was re-admitted less than a week later with chest
pain and APO, necessitating emergent dialysis. He was
depressed, dreaded the thought of further episodes of APO at
home and had contemplated suicide. A Psychologist diag-
nosed a major depressive episode and recommended anti-
depressant medication and psychotherapy. During the
admission Mr MF was unable to dialyse without episodes of
hypotension, precipitating early cessation of treatment. The
renal team introduced end-of-life (EOL) planning at a family
conference and negotiated an agreed not for resuscitation
order.

Four days after admission, Mr MF’s cardiologist trans-
ferred him to CCU to optimize his cardiac management. Mr
MF informed the renal team that he wished to stop dialysis
and his wife agreed, stating that her husband had discussed
during his last brief time at home. The renal team
doubted Mr MF had the capacity for decision making and
asked a psychiatrist to give a second opinion. The cardio-
ologist was uncomfortable with the patient’s decision and
asked Mr MF to continue dialysis until the anti-depressants
became effective. Mr MF requested his decision be
respected. Mr MF’s wife accused the cardiologist of bullying
her husband into ongoing dialysis. The cardiologist noted a
potential conflict of interest because Mr MF’s wife had pre-
viously divulged to him that Mr MF was physically and
verbally abusive towards her. Mr MF’s family articulated
distress at a family meeting with the renal and cardiac
teams that his wishes were not being respected and he was
being forced to dialyse. All agreed to await the outcome of
the second opinion of Mr MF’s capacity to make decisions
about end of life. Mr MF was not present at the family
meeting. Mr MF was deemed capable of EOL decisions by
a consultant psychiatrist.

The three medical teams – renal, cardiology and psychiatry –
met with the hospital solicitor because the cardiologist was
uncomfortable with the decision to withdraw dialysis. The
meeting reached a consensus of EOL care without dialysis
and the renal team spoke to the patient about cessation of
dialysis. Mr MF was referred to the consultative palliative
care team and was subsequently transferred from CCU to the
Renal Ward. The cardiologist remained distressed and asked
the patient and his wife to sign acknowledgement of refusal
of medical treatment. The renal inpatient team and palliative
care consulting team initiated the care of the dying pathway
and Mr MF died peacefully shortly after with his family in
attendance. The family sent a letter to the renal team a week
later thanking them for caring for Mr MF.

Nephrologist 1

This complicated medical case was compounded by distress
in the healthcare team. Members of the team disagreed
about treatment plans and the boundaries of the patient’s autonomy. The distress could not be resolved despite wide consultation with colleagues and legal involvement.

Nephrologist 2

This case demonstrates a number of problems frequently encountered by nephrologists

1 Advance discussions with nephrologists prior to procedures. This patient would have benefited by seeing a nephrologist before the renal artery angioplasty was attempted, allowing discussions of likely outcome and complications. The history suggests that the procedure was being attempted to reduce episodes of APO. This patient was known to have cardiac disease with ongoing angina and a blocked coronary stent. He therefore has potential mechanisms for pulmonary oedema unrelated to his renal arteries and thus raises the question of whether this procedure could be effective. The risk of complications is high – single kidney, high vascular burden – and the patient should have been informed of the risk of the need for dialysis induced by the procedure. He may have chosen not to go ahead in the first place. This raises the suggestion that fully informed consent was not obtained.

2 Complications of dialysis. If this patient had been seen by a nephrologist initially, he could have been assessed and informed of the potential benefits and complications of dialysis allowing him to make a choice and not being forced into a choice in an acute setting. He is a high risk patient – severe cardiovascular, renovascular and probable cerebrovascular disease with a difficult social setting. Dialysis did not relieve his cardiac symptoms and in fact exacerbated them. He was unable to tolerate dialysis due to blood pressure problems. Again – he could have been informed of this possibility prior to angioplasty which may have altered his decision.

3 Lack of appreciation by other health professionals of the difficulties associated with dialysis. Many renal physicians will have met patients who have been told that the nephrologists will put them on dialysis and all will be well, regardless of their other chronic diseases which may be worsened by the burden of dialysis as well as effects on quality of life (QOL). This suggests that we should be raising our profile in this area and educating our colleagues about renal replacement therapy and what it can truly offer.

4 Distressed colleague. It is interesting that the cardiologist remained distressed and opposed to the decision despite expert opinion from both nephrological and psychiatric colleagues. The cardiologist deserves follow up to allow him/her to discuss this. They may also benefit from knowledge of the letter from the family after the patient’s death.

5 Acknowledgement of the importance of quality of life, not just survival. With advances in medical technology, QOL can be forgotten. For most patients, how they feel is more important than the calibre of a blood vessel after dilatation. This needs to be included in medical training from the outset. This patient demonstrated an ability to make decisions, was judged as competent to do so and therefore needed to be acknowledged and allowed the autonomy to do so. The process he and his family went through probably added to their stress at a difficult time. He was aware of the detrimental effects of dialysis on his QOL and wished to cease. Eventually he was able to do so but it took a lot of discussion and disagreement before his wishes were acknowledged.

CASE 2. CULTURAL DIFFERENCES

Mrs BL was an 87-year-old Bosnian-Serb refugee from the Balkan wars, living with a devoted daughter who was her carer. She spoke no English and vested decision making in her doctors and two daughters.

Mrs BL was transferred from her local hospital with acute on chronic kidney disease (CKD) injury in the setting of community acquired pneumonia. Mrs BL had first seen a nephrologist a month earlier as an outpatient with newly diagnosed stage 4 CKD and proceeded to biopsy which reported non-diagnostic chronic thrombotic microangiopathy. Between the outpatient consultation, the day case renal biopsy procedure and now an acute hospitalization Mr BL encountered three different nephrologists.

All important conversations with Mrs BL took place through a hospital interpreter. However Mrs BL deferred all decision making to her daughters. Mrs BL’s daughters struggled with the uncertainties of the diagnosis, the competing risks and benefits of the biopsy informed consent process, the multiple management options and perceived differences of opinion between the three nephrologists. They agreed to an acute resuscitation plan that excluded admission to ICU.

Mrs BL’s urea reached 45 mmol/L and a dialysis access catheter was placed. However as the pneumonia resolved, so did the acute component of Mrs BL’s renal injury. The catheter was removed and Mrs BL was discharged home. Her daughters elected to defer decisions about future dialysis.

Two months later, Mrs BL was found to be fluid overload and had uremic symptoms at a routine outpatient appointment with her nephrologist. Her daughters requested that their mother receive haemodialysis. A dialysis catheter was placed and she started renal replacement therapy. Mrs BL was found to be vancomycin resistant enterococcus and therefore was dialysed in isolation. Her devoted daughter drove her to dialysis (60 min each way), remained with her for the 4 h of treatment and drove her home three days a week.

Nephrologist 1

Language, cultural and conflict (i.e. war) differences in this case were compounded by multiple healthcare providers giving messages that varied in perspective, even if not in content. The renal team seemed compelled to perform their obligation of full disclosure and informed patient participa-
tion by describing the spectrum of possibilities. This seemed to have been perceived as uncertainty or conflict amongst the team.

The patient’s daughters appeared to make decisions for their mother that were cognisant of her prevailing well being and not second guess her future. They did engage in difficult health decisions like no ICU admissions.

**Nephrologist 2**

This elderly lady obviously comes from a loving, caring family who are willing to give up their time to look after her. It would be interesting to know how she is doing on dialysis – some people do not experience many symptoms despite their age and comorbidities.

Acknowledgement of what has happened in this lady’s life and the role of her family are important in leading discussions with her and the family. The use of a hospital interpreter, not just relying on family, is essential to ensure that appropriate translation of information is occurring. It is important to discuss what is to be said with the interpreter first to make sure they have no cultural issues in disclosing information about EOL issues. Cultural differences surrounding uncertainty in medical prognosis can make discussions more complex and may result in decisions which the medical staff find difficult to accept. We need to acknowledge these differences and explore the best way to proceed.

Unfortunately, this lady was referred very late to the renal team, earlier referral could have allowed for more prolonged discussion about dialysis allowing the daughters to discuss it over months rather than having to make decisions once their mother had reached end stage. This would allow more time to explore cultural issues, hopes for the future, likely consequences of treatment, burden of care, QOL, etc. It would also have allowed a relationship to be developed with one nephrologist, gaining of trust and a consistent message. The fact that the daughters were able to make the decision about further ICU admissions, suggests that, with time, they may be able to discuss EOL issues further, such as dialysis withdrawal in the face of advancing symptoms or poor QOL. It is important now that she is followed up by a consistent nephrologist. In some units, follow up clinics may be run largely by registrars who will regularly rotate positions every few weeks to months which could further confuse the situation. This has implications both for continuity of care for the patient (conflicting messages from different doctors, repetition of interventions or investigations, etc.) and for junior doctor education in the management of patients with these problems. It is important that junior staff are included, to facilitate training and to give them experience of following through the patient journey, planning and monitoring longer term management and following the case through to end of life. Further discussions are likely to be needed and this lady will still need supportive care now she is on dialysis in order to alleviate symptoms, gradually explore advance planning further and allow appropriate care at the end of life.

**CASE 3. UNDER THE PATIENT’S CONTROL**

Mr RS was a 59-year-old divorced man, estranged from three adult children whom he had not seen for more than 15 years. He listed his next of kin as his general practitioner.

Mr RS was first referred to a nephrologist in 2008 with chronic kidney disease secondary to lithium, used to manage his bipolar affective disorder, when his serum creatinine was 212 μmol/L. A wide ranging discussion between Mr RS and his nephrologist about changes in life style as part of his end stage kidney therapy included restricting the volume of fluids, stop smoking and the need to schedule days to accommodate dialysis. Mr RS observed that he liked his beer and smokes too much and he would decline dialysis.

Over the next 4 years Mr RS attended appointments with his nephrologist and the palliative care team. During this time he was admitted to hospital eight times, for symptom control, hot food and contact with the nursing team. The social worker adjusted living accommodation as Mr RS’s frailty increased. The last days of Mr RS were in a religious hospice at his specific request.

**NEPHROLOGIST OPINION**

In this vignette, the patient was well known to the renal team for many years allowing time for discussions with his nephrologist about what was important in his life. This allowed management of his symptoms, acknowledgement and acceptance of his wish not to dialyse and ensuring that he was able to die in his place of choice. This case also demonstrates that age should not be seen as an issue. This was a patient who engaged with the team, expressed his wishes and was treated well. His age of 59 was not a deterrent to this pathway.

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