



Government of Western Australia  
Department of Health

# Renal Health Network

## Pathway for Renal Palliative Care Services in Western Australia

July 2012

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## Abbreviations

AHD	Advance Health Directive
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
CKD	Chronic kidney disease
EPG	Enduring Power of Guardianship
ESKD	End stage kidney disease
Functioning tx	Functioning transplant
HD	Haemodialysis
Home HD	Home haemodialysis
HRQOL	Health-related quality of life
KCAT	Kidney Check Australia Taskforce
KPI	Key performance indicator
MBD nurse	Mineral bone disease nurse
NEN	Nephrology Educators Network
Nephrology	Another word for renal
Nephrologist	Another term for renal physician
NSW	New South Wales
PEPA	Program of experience in the palliative approach
PD	Peritoneal dialysis
PCOC	Palliative Care Outcomes Collaboration
QoL	Quality of Life
RRT	Renal replacement therapy
SCGH	Sir Charles Gairdner Hospital
Tx	Transplant
WA	Western Australia
WA Lcp	WA Liverpool care pathway
WACHS	Western Australia Country Health Service
WHO	World Health Organisation

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## Executive summary

Chronic kidney disease, the progressive deterioration of the filtration ability of the kidneys, is a common disease in Australia.<sup>1</sup> End stage kidney disease (ESKD) also called end stage renal failure is when the kidney fails completely to function. The disease is irreversible and there is no cure. The only treatment is in the form of dialysis or kidney transplant termed renal replacement therapy (RRT). Dialysis is the most common form of treatment and the main reason for hospitalisation.<sup>1</sup> It is responsible for a large amount of health expenditure.

The increasing incidence of ESKD in Australia poses a major public health problem. Patients with ESKD have a higher mortality, more significant symptom burden and poorer quality of life (QoL), irrespective of whether they opt for RRT or not. A conservative (non-dialysis) path is often chosen by patients with ESKD, who are generally older and with multiple comorbidities. The intentions and outcome of these groups of patients are not well documented. Further, without a clear plan, unnecessary medical interventions are initiated that may cause significant distress to patients and their families/carers.

There is an increasing awareness among renal physicians that palliative care is not just end-of-life management but rather a supportive care pathway leading over time to a dignified end of life for an individual patient. The concept of a renal palliative care service within the renal unit to provide supportive care to patients, their family and carers in addition to their usual renal care is not new. However, the actual delivery in Western Australia (WA) is inconsistent as there is no systematic and formalised pathway model.

There is a crucial need to provide a consistent best practice, protocol-driven service that could address and manage issues such as distressing symptom burden, poor quality of life and also facilitates end of life discussions with an agreed pathway to a dignified end of life for every patient with ESKD.

This document describes a care pathway for the establishment of an integrated patient-centric multi-disciplinary renal palliative care service. The service has a strong linkage with the palliative care team and primary care practitioners, with active involvement of the patient and carers in decision making. The service encompasses patient and family education, symptom management protocols, advance care planning, Liverpool Care Pathway for the last days and hours of life, and finally bereavement support.

Renal physicians and renal nurses have limited training and variable exposure to palliative care. Palliative care training for renal advanced trainees is also deficient. This document outlines the education and training requirements, identified education tools, curriculum content and delivery methods to provide clinicians with the necessary skills and knowledge to facilitate the necessary discussions and administer the best practice on-going symptom management through end of life care.

## Key recommendations

1. Establish a combined renal and palliative care service within the renal unit in each tertiary hospital.
2. Extend the service to the rural and remote regions utilising the links and framework developed by the Cancer and Palliative Care Network.
3. Ensure the combined renal and palliative care service is patient-centred and complementary to the WA Palliative Care Model of Care.
4. Consider the following groups as suitable candidates for the renal palliative care service:
  - Patients with advanced CKD who have opted for conservative management.
  - Patients with advanced CKD who are considering withdrawal from Renal Replacement Therapy (RRT).
  - Patients with advanced chronic kidney disease (CKD) with unresolved symptoms affecting quality of life (QoL).
  - Patients using dialysis who have exhausted all options for on-going dialysis access, for example: peritoneal dialysis (PD), catheter or arterio-venous fistula methods.
  - Patients with declining transplant graft function who have opted not to return to dialysis therapy.
  - Patients with advanced CKD who have other life-limiting comorbidities resulting in physical and functional decline. For example: malignancy, end stage cardiac and / or respiratory disease, Alzheimer's disease.
5. Use assessment tools for symptoms and quality of life measurement to monitor symptom burden, patients' progress and effectiveness of the service provided.
6. Incorporate palliative care into the renal trainee curriculum in WA.



## 1. Background and methodology

Renal palliative care was identified as a priority at the WA Renal Health Network stakeholders' forum held on 12 May 2011.<sup>2</sup> A working group was formed in July 2011 to develop an implementation pathway for a combined patient-centric renal and palliative care service that is complementary to the Palliative Care Model of Care<sup>3</sup> and the Rural Palliative Care Model in Western Australia.

Members of the working group registered through an expression of interest process. They represented the government and non-government sectors which included interdisciplinary health professionals such as renal physicians, renal nurses, social workers, medical practitioners in Aboriginal Health and health service managers. A carer and consumer who had experiences with renal care and recently palliative hospice care participated in the working group to provide valuable insight and perspectives of the patient and from the family.

The working group worked closely with the WA Cancer and Palliative Care Network to develop the renal palliative care pathway.

The working group examined:

1. The current burden of ESKD.
2. The need to integrate both palliative care and nephrology services.
3. The establishment of a renal palliative care service.
4. An appropriate referral pathway to the proposed service.

The working group reviewed current literature, analysed current service delivery both in metropolitan and rural Western Australia (WA) to develop the renal palliative service model and implementation pathway based on existing National and International services.

## 2. Burden of end stage kidney disease

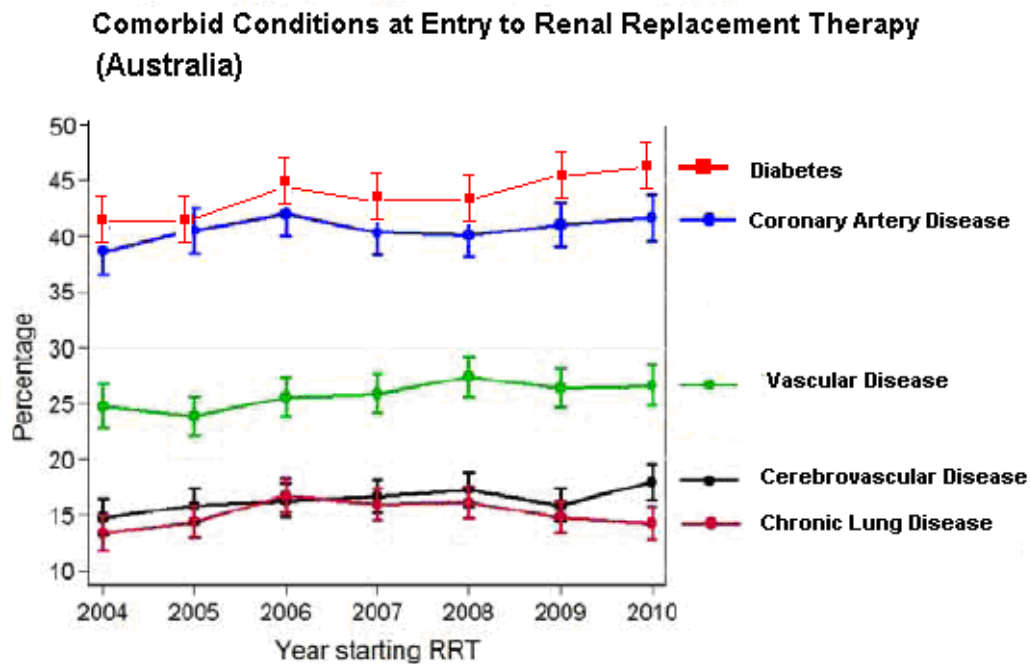
The incidence of treated ESKD in Australia is projected to increase by 80% from 11 per 100,000 population in 2009 to 19 per 100,000 population in 2020.<sup>1</sup> The largest growth is projected to be amongst the elderly, who are dependant, frail and with multiple co-morbidities such as diabetes cardiovascular and peripheral vascular disease (Figure 1). Diabetes is expected to contribute considerably to the increase in treated ESKD from 45% in 2009 to 64% in 2020.<sup>1</sup>

The latest data indicate that at the end of 2010, there were 18,999 Australians with ESKD receiving renal replacement therapy (RRT).<sup>4</sup> Of these, 8,409 had a functioning kidney transplant and 10,590 were receiving dialysis treatment (Figure 3). 2257 new patients received renal replacement therapy in the year 2010.

The highest dialysis prevalence groups are in the 65-74 year age group (24%) and those over 75 years (24%).<sup>5</sup> In the past five years, the greatest percentage increase in acceptance onto dialysis has been in the 85 and over age group.<sup>6</sup>

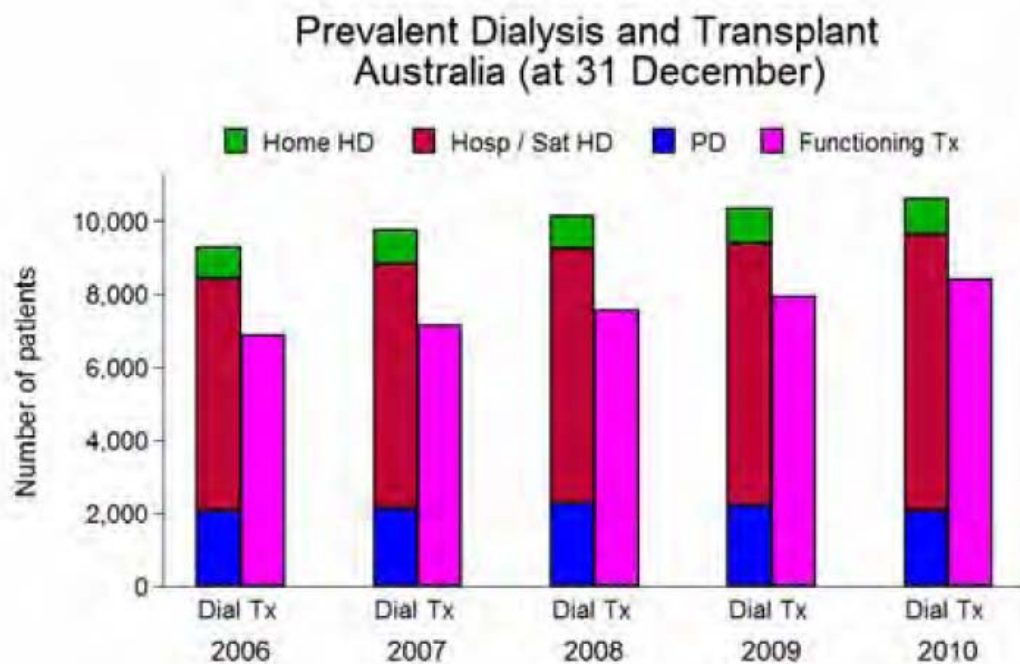
In WA, there were 1825 people receiving RRT at the end of 2010. Of these, 818 had a functioning kidney transplant and 1007 were on dialysis treatment. During 2010, 226 new patients received RRT. Of these new patients 43% were above 65 years of age (19% in 65-74 yr age group, 20.8% in 75 -84 yr group and 2.65% in the 85-94 yr age group).<sup>7</sup> In 2010, 70% of the patients initiating RRT required hospital haemodialysis as their initial modality of dialysis.

**Figure 1: The Percentage of people starting renal replacement therapy with comorbidities**



Source: ANZDATA report 2011

**Figure 2: Number of people on dialysis and with kidney transplant at the end of December 2010**



Source: ANZDATA report 2011

(Dial – dialysis; Tx – transplant; Home HD – home haemodialysis; Hosp/Sat HD – hospital/satellite; PD – peritoneal dialysis; Functioning Tx – functioning transplant)

## 2.1 Aboriginal patients

The ESKD rate among the Aboriginal population is 30 times higher than the non-Aboriginal population and occurs in considerably younger age groups. In WA, at the end of 2009, 345 (19.5%) Aboriginal patients were on RRT with 299 patients on dialysis and 46 with functioning transplants. During the year, 37 (16%) started RRT and there were 38 deaths. Increasing co-morbidities and mortality in this population indicates the need for palliative services in a culturally acceptable manner in or nearer to their communities.

## 2.2. High mortality rate

International data show extremely high mortality in elderly patients initiating dialysis therapy, with the highest mortality rates in the United States, Australia and New Zealand.<sup>8</sup> Many patients with CKD especially older patients over 65 years will have one or more co morbid conditions when referred to a nephrologist. Not only is co-morbidity a powerful predictor of early and late mortality in CKD patients, the severity of the co-morbid condition will directly impact on the patients health-related quality of life (HRQOL).<sup>9</sup>

An overall mortality rate in all patients receiving dialysis in Australia during 2010 was 13.42 per 100 patient years. Significantly higher mortality occurred in the elderly population, patients with Type 2 diabetes, and patients with established heart disease at the initiation of RRT. Renal service providers and nephrologists are recognising that dialysing those with increasing dependency and multiple comorbidities does not improve their survival and may adversely affect their quality of life and prolong their suffering.<sup>6</sup> Also, survival advantage of dialysis in the very elderly is of no benefit when there is a high co-morbidity score, poor functional ability and high social dependency.

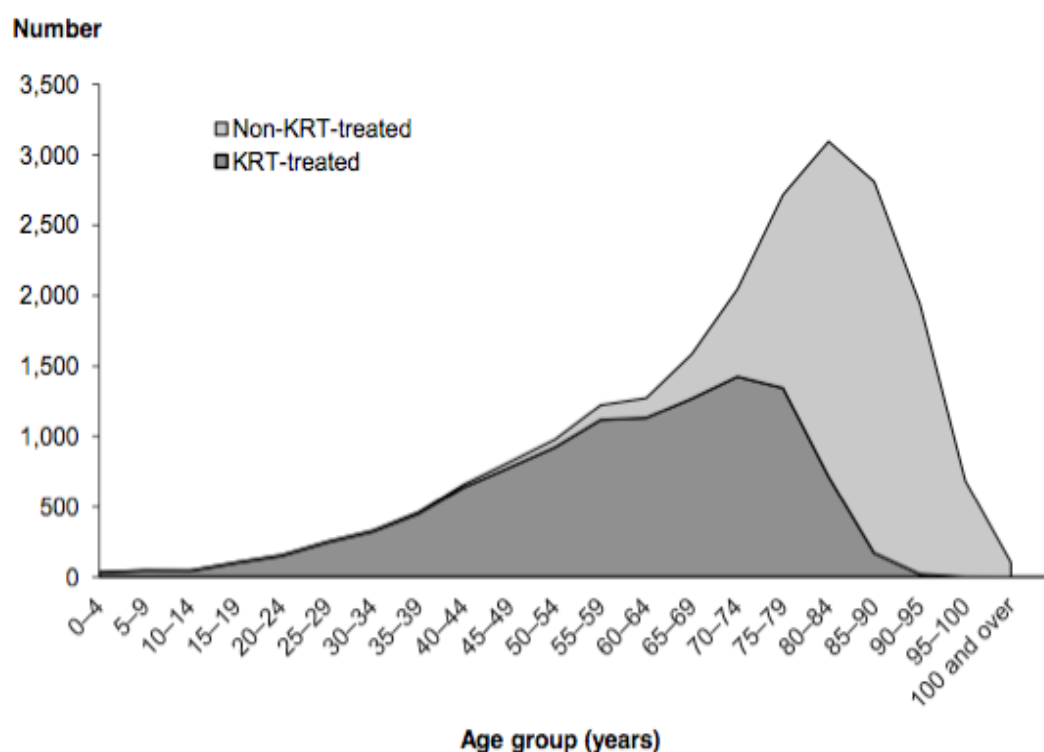
## 3. Renal conservative management non-dialysis approach

Fassett et al<sup>10</sup> recommend that discussions about a conservative management supported by palliative care should be offered to those with multiple co-morbidities. They believe that patients and their families may struggle to choose not to commence dialysis treatment or elect to withdraw from it in the absence of an integrated palliative care service. Hence, information about palliative care options should be included in pre-dialysis education.

Conservative management entails appropriate and careful management of specific advanced CKD symptoms of anaemia, metabolic bone disease, blood pressure management, blood glucose control, electrolyte abnormality and symptoms of uraemia.<sup>11</sup> Conservative management should also incorporate community and palliative support services to maximise quality of life until the terminal phase of life is reached. At this point specialised supportive care should be provided with particular attention directed to bereavement care for the family following the patient's death.

A conservative approach to the management of CKD may be more appropriate for some patients with advanced CKD Stage 4 & 5, who have opted not to have RRT. Many renal units across the world are offering conservative management as a recognized treatment option.<sup>12 13</sup> The ratio between ESKD patients that opted for RRT and those who did not was 1:1.<sup>1</sup> Patients who were treated conservatively were more likely to be in the older age group (Figure 4). As these patients experience deterioration in their general health and increased frailty, the management focus should be shifted towards advanced care planning and planning for end of life care. Establishing a specialist renal-palliative care clinic within the renal unit would serve this need.

**Figure 3: Number of renal (kidney) replacement therapy and non-renal (kidney) replacement therapy cases by age group at ESKD onset 2003-2007**



Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.

Non-KRT – Non kidney replacement therapy; KRT – kidney replacement therapy

### 3.2. Poor Quality of life and high symptom burden

The number and severity of uraemic symptoms such as fatigue, pruritus, dry mouth and thirst, pain, nausea and vomiting, anorexia, shortness of breath, insomnia, cramps, restless legs, insomnia and depression have been compared to those of ESKD patients with cancer patients.<sup>11</sup> These symptoms are often difficult to control effectively. Total symptom burden is high with limitations of the use of certain pharmaceutical agents normally used to control symptoms due to renal impairment and reduced renal excretion. Pain severity in stage 5 CKD patients is often poorly recognized and treated ineffectively.<sup>14</sup>

### 3.1 Comparative study of dialysis versus non dialysis treatment

A survey of 105 patients in 8 Renal Clinics in Australia showed that patients approaching end-stage kidney disease are willing to trade considerable life expectancy to reduce the burden and restrictions imposed by dialysis.<sup>15</sup> Patients were willing to forgo 7 months of life expectancy to reduce the number of required visits to hospital and 15 months of life expectancy to increase their ability to travel. Increased life expectancy, flexibility in the dialysis timings and subsidised transport had positive influence towards choosing dialysis whilst the number of hospital visits and restrictions on their ability to travel influenced the decision to opt for conservative management.

The survival advantage of dialysis is substantially reduced by comorbidity. Murtagh and her colleagues<sup>16</sup> conducted a comparative study on conservative treatment versus dialysis treatments in Stage 5 CKD patients over 75 years of age, who received specialist nephrological care early and followed a planned management pathway. At the end of 2 years, elderly patients who received dialysis had median survival benefit of only 48 days. In patients with ischaemic heart disease, there is no evidence that a decision to follow a dialysis pathway results in an improvement in survival. Comorbidity should be a major consideration when advising elderly patients for or against dialysis.<sup>10</sup>

An American study in nursing home patients on dialysis showed that only 13% of these patients maintained their pre-dialysis functional state after commencement of dialysis, with 39% having reduced functional status, while 58% died in the first year.<sup>17</sup> Predictors of death in the elderly dialysis population were poor nutritional state, late referral, multiple-morbidities and functional dependency. Withdrawal of dialysis represented 35% of deaths.

## **4. Patient decision making**

### **4.1. Ethical principles of dialysis decision making**

The application of the ethical principles of respect for patient autonomy, beneficence, not doing harm, justice and professional integrity are paramount.<sup>18</sup> The process of shared decision-making about starting, withholding, continuing, and stopping dialysis with patients and families must adhere to these ethical principles. However, appropriate limits to shared decision-making must be acknowledged when medical indications predict that the burdens of dialysis substantially outweigh the benefits.

### **4.2. End of life preferences**

The United Kingdom (UK) developed a Gold Standard Framework (GSF)<sup>19</sup> to deliver a 'gold standard of care' for all people nearing the end of life. "It is about living well until you die". The key message is that end of life care is important and at one time or another all people will be affected in relation to decision making regarding the health of a loved one, family member or in regards to one's own health status. In Australia, "The guidance document - Health System Reform and Care at the End of Life"<sup>20</sup> represents a shared vision for the development of high-quality palliative and end of life care in Australia.<sup>21</sup>

Current end-of-life clinical practices do not meet the needs of patients with advanced CKD.

A survey of Canadian patients on end of life preferences and needs<sup>22</sup> found that around 80-85 % patients wanted to be informed of treatment options, including withdrawal from dialysis. 35% would like the nephrologist to make the decision on their behalf, if incapacitated. Although most patients reported being comfortable discussing end of life issues, over 90% reported that the nephrologist had not discussed prognosis with them. Participants also had poor self reported knowledge of palliative care options and of their illness trajectory. A total of 61% of patients regretted their decision to start dialysis. Many reported the decision of dialysis was reflective of medical and family members' wishes. Most patients wanted end of life care to treat pain and suffering rather than treatment to extend life. 50% relied on the nephrology team (doctors and nurses) for extensive end of life care needs such as pain and symptom management, advance care planning, and psychosocial and spiritual support. Only 38% had completed an Advance Health Directive.

### 4.3. Advance care planning

Any supportive model of care needs to attend to end of life discussion and advance care planning. Advance care planning allows competent patients to record their wishes for treatment that they would or would not want, if at some future time, they are no longer competent to make such decisions.<sup>23</sup> Advance Care Planning includes decisions in relation to Advance Health Directive (AHD), Enduring Power of Guardianship (EPG), Not for Resuscitation (NFR) orders, organ donation and allows individuals to make decisions regarding medical and surgical treatments that they would or would not want to receive. Patients may wish to nominate a substitute decision maker, by completing an Enduring Power of Guardianship, giving authority to another person to make personal, life style and treatment decisions on their behalf, if they are unable to do so in the future.

#### Goals for advance care planning in ESKD are to:<sup>22</sup>

- Enhance patient and family understanding about illness and end of life issues including prognosis and likely outcome of alternative plans of care.
- Define the patients' key priorities in end of life care and develop a care plan that addresses these issues.
- Enhance patient autonomy by shaping future clinical care to fit the patients' preferences and values.
- Improve the process of healthcare decision making generally, including patient and family satisfaction.
- Provide an opportunity to nominate a substitute decision maker.
- Promote shared understanding of relevant values and preferences amongst the patient, substitute decision maker and healthcare providers.
- Help patients find hope and meaning in life and help them achieve a sense of spiritual peace.
- Explore ways to ease emotional and financial burdens borne by patients and families.
- Strengthen relationships with loved ones.

### 4.4. Cultural awareness

Planned services need to be aware of utilising culturally sensitive care to the various minority groups within multi-cultural Australia. Appropriate use of relevant information and recognition of barriers within each ethnic group is crucial to the implementation of a renal palliative care service in these specific populations. The Kimberley Aboriginal Medical Council and the Northern Territory Department of Health have developed excellent resources for Aboriginal renal patients.

## 5. Palliative care approach

The World Health Organisation (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with 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.”

<http://www.who.int/cancer/palliative/definition/en/>

Palliative care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor to postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Enhances the quality of life, and may also positively influence the course of illness.
- Introduced early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is sometimes referred to as ‘supportive care’ and the goal is to achieve the best possible quality of life by controlling symptoms, relieving pain and restoring functional capacity whilst respecting the patients personal, cultural and spiritual beliefs and practices.<sup>24</sup>

The traditional belief that palliative care is associated with only end of life care remains very firm in the general community. Providing palliative care to patients with advanced CKD begins at the time of diagnosis and continues throughout the patient’s life. Palliative care assumes increasing importance with time and is integral to “good deaths” as the disease progresses.<sup>25</sup>

## 6. Integration of palliative care into end stage kidney disease

The need to extend the philosophy of palliative care services beyond cancer care to encompass care for all people with a life limiting illness is now internationally recognised.<sup>11</sup> Every person regardless of age or diagnosis has a fundamental right to care that is underpinned by a palliative approach.<sup>3</sup> The National Palliative Care Strategy 2010 supports this philosophy<sup>26</sup> and is consistent with the Declaration of Montreal that access to pain management is a fundamental human right. <http://www.ncbi.nlm.nih.gov/pubmed/21426215>

As patients develop progressive CKD to stages 4 and 5, both physical and psychological life limiting symptoms increase. A shared care approach with renal and palliative multidisciplinary teams working together to provide a holistic approach to meet the needs of these CKD patients and their families is imperative.<sup>27</sup> With increasing awareness of the need for a systemic renal-palliative care framework, international guidelines have been developed and utilised to improve and implement high quality end of life care for CKD patients and their families.<sup>9, 13</sup> The integration of palliative care with other chronic diseases is now well advanced in most countries. In Australia renal palliative shared care services are commencing in some centres in New South Wales,<sup>28</sup> Tasmania and Northern Territory.

In order to improve the quality of life in people with advanced CKD, renal teams need to:

- identify patients who may have 6 months or less to live
- communicate prognosis, discuss conservative management with the patient, family/carers and relevant health care providers and ensure appropriate supportive care is in place
- recognise the symptom burden in patients with advanced CKD<sup>29</sup> and provide appropriate symptom management, support and care

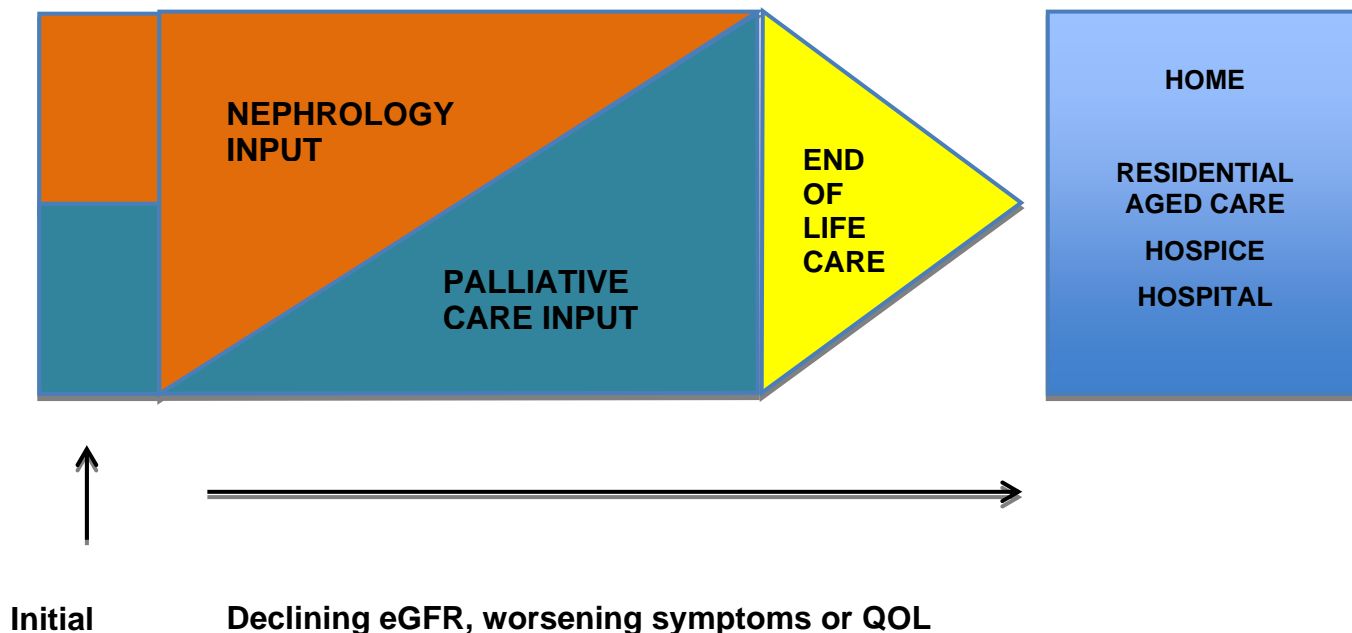
Assessment tools to identify patients and symptom burden are described in Section 9.



## 7. Proposed renal palliative care model

The proposed model is depicted in figure 5 below.

**Figure 4: Shared care model of renal palliative care service**



(eGFR – estimated glomerular filtration rate)

The renal palliative care clinics will be established initially at tertiary hospitals in tandem with the standard nephrology care. The care priorities will be determined by the patient and family needs. The shared service is patient-centred and is based on the following model:

- Case managed and led by a senior renal nurse in partnership with renal services, palliative care services, which include community-based support organisations such as Silver Chain, multi and inter disciplinary team, GP and relevant medical specialists.
- Patients can be referred to the service by a renal nurse, GP, a nephrologist and allied health professionals.
- The service is a contact point for the GP, patient and family to facilitate effective communication between the service, GP, community based support services and relevant specialists.
- The senior renal nurse acts as the communication channel for the essential members of the team.

## 7.1. Essential members of the service

- nephrology team (consultant and registrar)
- palliative care team (consultant, registrar or specialist nurse)
- General Practitioner
- CKD nurse (case manager)
- social worker
- dietitian
- Aboriginal liaison officer
- occupational therapist

## 7.2. Renal palliative care referral pathway

The recommended referral pathway is shown in figure 6:

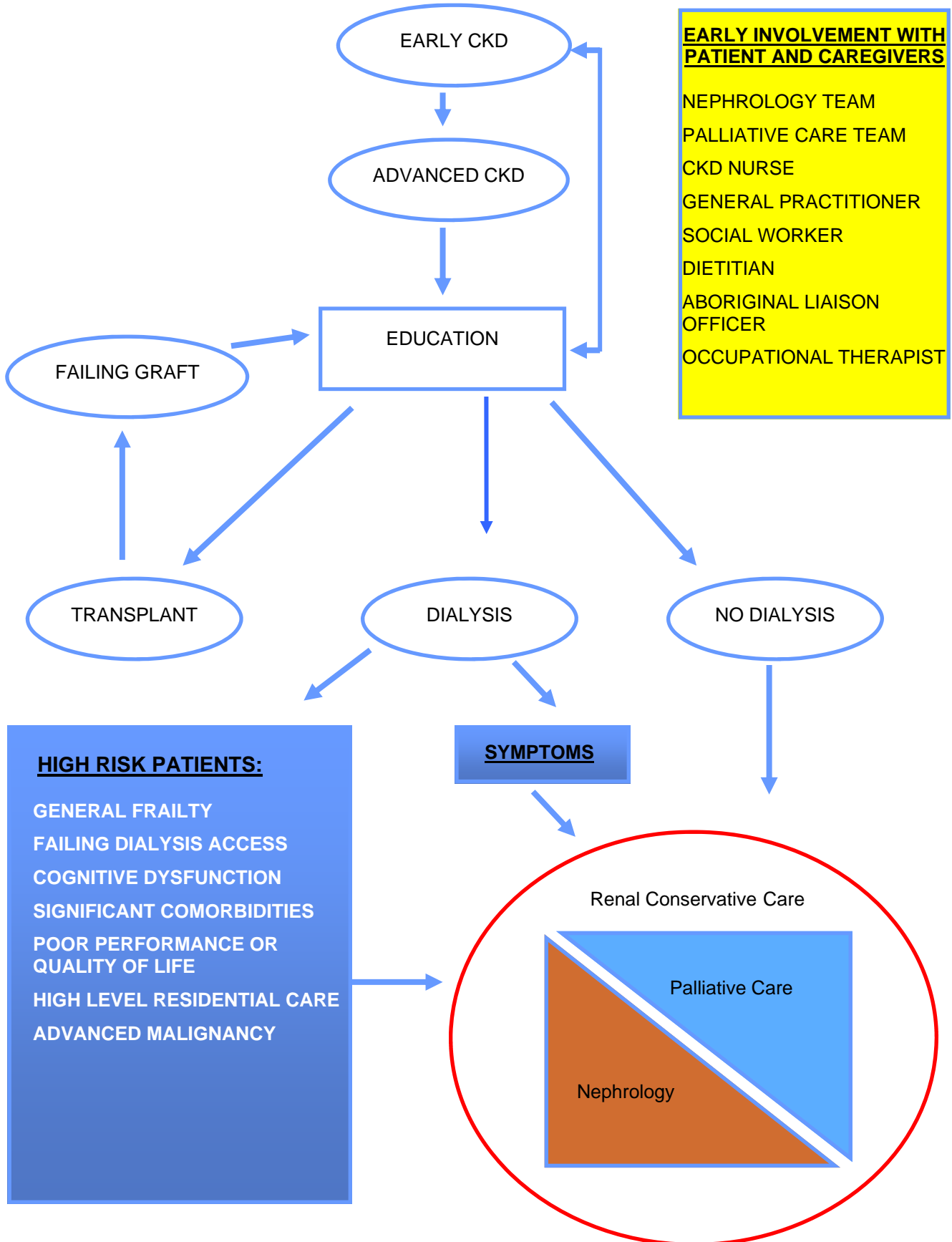
- Early involvement of patients and care givers is essential at the initial visit to introduce concept of palliative care and provide information regarding the services that are available.
- Subsequent follow-up of patients depends on patient's needs as depicted in the pathway.

## 7.3. Target group

Patients who are considered suitable for palliative care include the following:

- patients with advanced CKD who have opted for conservative management.
- patients with advanced CKD who are considering withdrawal from RRT.
- patients using dialysis who have exhausted all options for on-going dialysis access for example peritoneal dialysis (PD) catheter or arterio-venous fistula methods.
- patients with declining transplant graft function, who have opted not to return to dialysis therapy.
- patients with advanced CKD who have other life-limiting comorbidities resulting in physical and functional decline for example malignancy, end stage cardiac/respiratory disease, Alzheimer's disease.
- dialysis patients who are at high risk of mortality and morbidity, that is those with multiple comorbidities, general frailty (based on Fried frailty criteria),<sup>30</sup> cognitive dysfunction, high level residential care, and poor quality of life (QoL).

**Figure 5: Recommended referral pathway**



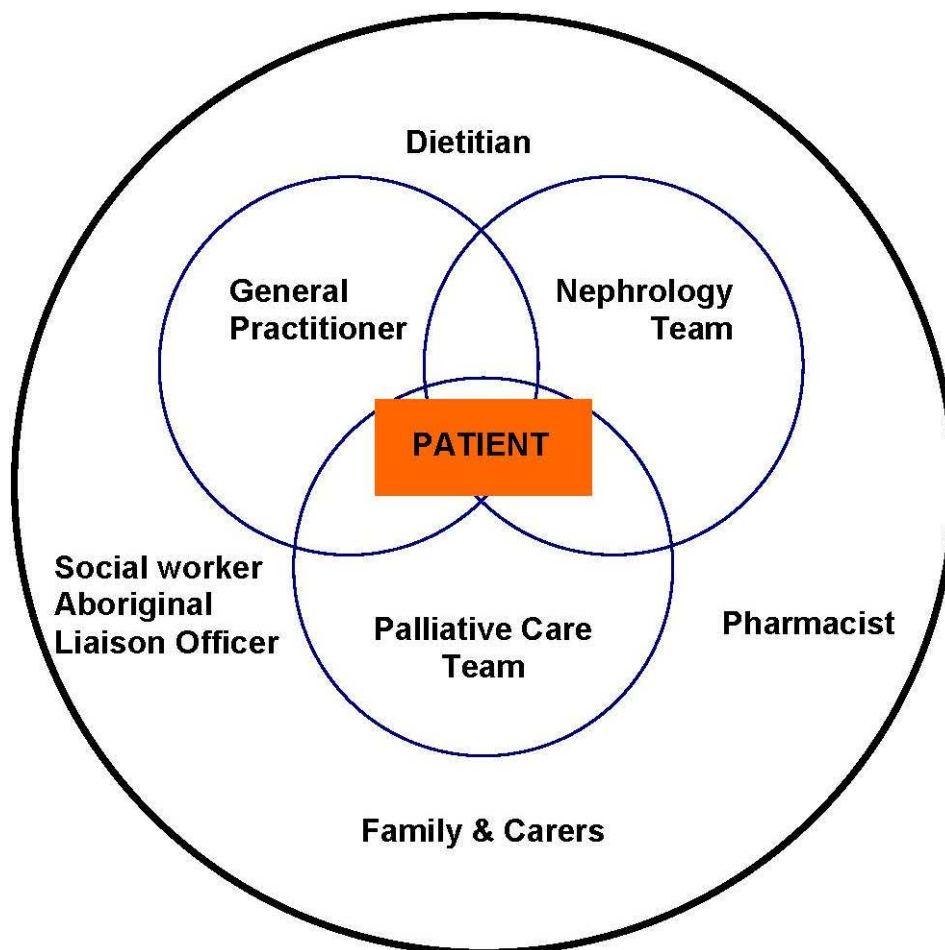
## 8. Patient centred approach

The education of relevant health care providers regarding the importance of an integrated multidisciplinary renal palliative care approach in the overall care of patients with ESKD is essential.

As depicted in figure 7, the patient is the focus of care, based on the following principles:

- Encourage patient and family to be actively involved in the decision making process.
- Develop good and open 2 way communication with patient, caregivers and GPs regarding prognosis, expectations and other issues which may arise.
- Recognise and manage debilitating symptoms to improve patient's functionality and quality of life.
- Manage the patient's symptoms based on highest level of clinical evidence.
- Facilitate timely withdrawal from dialysis when indication arises.
- Introduce advance health care directives.
- Introduce early palliative care support and services that are available.
- Facilitate smooth transition to end of life care by early decision making and referral to community palliative care or hospice services to avoid unnecessary hospital admissions.
- Create referral pathway for access to local palliative care services for remote patients.

Figure 6: Patient-centred approach



## 9. Assessment tools

Regular ongoing assessments in palliative care clinical practice have the potential to:<sup>31</sup>

- enable consistent monitoring of disease status and prognosis
- evaluate the effectiveness of interventions
- assess symptoms accurately to ensure appropriate clinical management
- ensure better quality discussions around the concerns and priorities as described by the patient
- enable quality improvement process across sites

Listed below are some of the tools available. It will be at the discretion of the units to choose the most appropriate tool for their patients' need.

### 9.1 Symptom assessment

The Palliative care Outcome Scale (POS) is a tool to measure patients' physical symptoms, psychological, emotional and spiritual needs, and provision of information and support at the end of life.

POS is a validated instrument that can be used in clinical care, audit, research and training.<sup>32</sup> This tool has been validated for use in renal disease by Murphy et al<sup>33</sup> and is currently used by St George renal palliative care service in New South Wales (NSW).

### 9.2 Quality of life assessment

#### 9.2.1. 36-Item Short Form Health Survey

As part of the Medical Outcomes Study (MOS), a multi-year, multi-site study to explain variations in patient outcomes, RAND Health Corporation developed the 36-Item Short Form Health Survey (SF-36). SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilised by managed care organizations.

All of the surveys from RAND Health are public documents, available without charge for non-commercial purposes.<sup>34</sup>

#### 9.2.2. The Kidney Disease Quality of Life 36 questionnaire

The KDQOL-36 (Kidney Disease Quality of Life) questionnaire is the recommended annual assessment tool for patients with ESKD in the United States. This questionnaire combines components from the original SF-36 (physical and mental components) with essential aspects relevant to patients with ESKD such as symptoms, illness burden, social interaction and patient satisfaction. The questionnaire is simple and completed by the patient and has an online scoring system. This tool is available for purchase online via [www.KDOL-COMPLETE.org](http://www.KDOL-COMPLETE.org).

### 9.3 Palliative care outcomes collaboration (PCOC)

Specialist palliative care services are now recognized as an integral component of contemporary healthcare. Systems for monitoring and ensuring the quality of such services are considered essential. The Palliative Care Outcomes Collaboration (PCOC) commenced in 2005 in Australia as an ongoing national quality improvement initiative for palliative care. The initiative is based on a model that emphasizes outcomes measurement as a routine part of clinical practice, a comprehensive description of which has been reported elsewhere.<sup>31</sup>

The use of standardized approaches to clinical assessments, and a common language associated with these agreed assessment approaches, enhances communication between health professionals and is also a mechanism for reliable communication with patients.<sup>31</sup>

The five clinical tools that constitute the assessments within the current PCOC dataset reflect the core domains of physical, social, emotional, and well-being that palliative care encompasses.<sup>35</sup>

These assessments include:

[Phase definition](#) : Used as a prognostic indicator to identify & manage care

[RUG-ADL definition](#) : The physical stage of independence vs dependence in relation to the presence of a disease process

[Problem Severity Score definition](#) : scoring individual symptoms & management

[Karnofsky definition](#) : Individual performance ability

[Symptom Assessment Scale definition](#) : domains of care score for pain, other symptoms, psychological and spiritual and family/carer

## 10. Key Performance Indicators on treatment and outcomes to monitor patient care

Key Performance Indicators (KPIs)	Scope	Measure	Target
<p><b>1. Participation in program:</b></p> <p>1. Percentage of patients that have a symptom scoring tool completed once every 6 months</p> <p>2. Percentage of conservative managed care patients who attend a palliative care clinic per year</p>	<p>Data required: entry into a database recording completion of symptom scoring tool and the score achieved</p> <p>Data entry of clinic attendance</p>	<p><b>Numerator:</b> scoring tool completed</p> <p><b>Denominator:</b> Number of patient on dialysis</p> <p><b>Numerator:</b> Number of clinic visits</p> <p><b>Denominator:</b> Number of conservatively managed patient</p>	<p>100%</p> <p>60%</p>
<p><b>2. Effectiveness of program:</b></p> <p>Proportion of patients who have completed an advance health directive (AHD)</p> <p>2. Proportion of patients who have an end of life pathway determined &gt;1 month prior to death</p>	<p>Data entry on handout &amp; completion dates</p> <p>Entry into database when pathway was discussed and finalised when death occurred</p>	<p><b>Numerator:</b> AHD completed</p> <p><b>Denominator:</b> AHD handed out to patients</p> <p><b>Numerator:</b> Deaths with a pathway</p> <p><b>Denominator:</b> Number of deaths</p>	<p>60%</p> <p>60%</p>

## 11. Terminal care - Liverpool Care Pathway

The Liverpool Care Pathway for the dying patient (LCP) was developed by the Marie Curie Palliative Care Institute, Liverpool UK, to improve care of the dying in the last days and hours of life for patients, their families and friends. <http://www.mcpcil.org.uk/>

The LCP is recognised internationally, provides a quality improvement framework to support best practice in care of the dying patient, irrespective of diagnosis or the setting of care. In 2008 the WA Cancer and Palliative Care Network selected and adapted the LCP (the WA lcp) for use across West Australia.

[http://www.healthnetworks.health.wa.gov.au/cancer/docs/WA\\_lcp\\_Information\\_sheet\\_AHPs.pdf](http://www.healthnetworks.health.wa.gov.au/cancer/docs/WA_lcp_Information_sheet_AHPs.pdf)

The WA lcp prompts the health care team to implement goals of care to ensure optimum patient care and family support in the last hours or days of life, when the patient's death is expected. Key pathway areas include initial and ongoing assessment and care after death.

The goals of care support symptom control, comfort measures, pre-emptive prescribing and review of care, including psychological and spiritual care and care of the family before and after the death of the patient. Care is agreed upon by the multidisciplinary team, patient and family and is planned to meet the unique needs of the patient.

The WA lcp provides organisations with a sustainable quality framework for reflective practice and continuous quality improvement in the care of the dying through the use of clinical audit. The WA lcp is supported by the WA Palliative Care Resource Kit, containing a suite of evidence based resources developed by a WA Palliative Care Network expert working group. This includes evidence based protocols for dyspnoea, nausea and vomiting, pain, respiratory tract secretions and terminal restlessness/agitation.

The WA lcp continues to be rolled out the in metropolitan, rural and regional health services. The outcomes of formal evaluation have demonstrated improvements in symptom management, documentation, communication and caregiver satisfaction.

## 12. Education and training requirements

Currently there is variable but generally little exposure to palliative care in medical, nursing nephrology course and advanced renal training. This lack of training ranges from the skills required to initiate and facilitate appropriate discussions and administer the highest quality ongoing symptom management through to end of life care.

As previously stated in section 13, the project officer will develop and facilitate early delivery of a comprehensive education program that delivers education at varied levels, depending on the role of the individual health professional. Close linkage with palliative care services will support this aspect of the roll-out.



## 12.1 Education needs of practitioners at the different levels:

Level 1 - Expert	Level 2 - Experienced Practitioner	Level 3 - Support Practitioner
<ul style="list-style-type: none"> <li>▪ Palliative care nurses and physicians</li> <li>▪ Level 3 Renal Unit leaders, expert specialist nurses, nurse educators and nurse practitioners</li> <li>▪ Nephrologists and registrars:</li> </ul> <p>This group would have expert skills to identify the need for communication and the management of those requiring palliative care services.</p>	<ul style="list-style-type: none"> <li>▪ Level 2 dialysis and renal ward nurses</li> </ul> <p>This group would require training sessions in the application of all of the palliative care tools and the palliative care pathway.</p> <p>For those with a special interest in palliative care more advance training could be offered.</p>	<ul style="list-style-type: none"> <li>▪ Level 1 renal nurses</li> <li>▪ Aboriginal Health Workers:</li> <li>▪ Allied Health</li> </ul> <p>Social workers and key Aboriginal health care workers may require education at a higher level.</p> <p>Nurses, allied health and all Aboriginal care workers should be aware of the program and be able to adapt their patient care depending where the patient is on the palliative care pathway.</p>

## 12.2 Curriculum

A suggested general curriculum would include but is not exclusive to the following:

- communication skills related to discussing end of life planning and discussing of un-managed symptoms
- when to withdraw dialysis
- clinical symptom management
- understanding and the application of renal palliative care tools
- bereavement process and support skills
- special needs of local cultural groups

## 12.3 Education tools:

- the W.A. Palliative Care Model of Care
- patient symptom assessment tool(s)
- initiating palliative care discussions information guide
- Advance Health Directives (optional tool within main pathway)
- Liverpool Care Pathway (last few days and hours of life)
- awareness of WA palliative care resource kit – includes flip chart on symptom management that can be adapted for renal if required

## 12.4 Education delivery:

The following options maximise the use of existing education programs:

- Integrate the renal palliative care pathway into the current physician training courses for Nephrology Registrars (Nephrology advanced training curriculum).
- Utilise an exchange program between the Palliative Care and Renal Registrar's advanced training.

- Obtain nursing palliative care competency through secondments to “Centres of Excellence” and advance training through completion of palliative care diplomas. The development of specialised renal palliative care diplomas for nurses and physicians should be a future goal (consider the NSW St George hospital model).
- Introduce palliative care as an elective unit in the Nephrology course.
- Attend the Journal club; held monthly amongst palliative care medical specialists and senior palliative care nurses.
- Attend the existing palliative care study days made available through tertiary teaching hospitals and the Cancer Council WA.
- Participate in the current Liverpool Care Pathway (LCP) training sessions. The LCP is being rolled out as a fully funded 18 month training program at Fremantle Hospital from Nov 2011 and at SCGH -commencing in 2012.
- Participate in an Advance Care Planning program.
- Develop a website or webpage on an existing site with details of available courses. For example, the Nephrology Educator’s Network (NEN) has promoted a standardised, and evidence based approach to nephrology education that aims to avoid the duplication of resources while also encouraging knowledge sharing between organisations. These inter-organisational partnerships support nurses caring for people with kidney disease throughout Australasia including those in remote communities. <http://www.nen.org.au>
- Utilise the Program of Experience in the Palliative Approach (PEPA). PEPA aims to:
  - improve the quality, availability and access to palliative care for people who are dying, and their families by improving the skills and expertise of health practitioners
  - enhance collaboration between service providers
- PEPA offers:
  - supervised clinical placements in specialist palliative care services in the community and inpatient settings
  - integration of learning into practice
  - post-placement support
  - tailored workshops
- Dedicate time within the Rural Palliative Care Specialist Group (representing the seven WACHS areas) bimonthly meetings for linking with renal nurses and renal training. This would be in collaboration with the WA Palliative Care Network.
- Promote the development of Kidney Health Australia’s KCAT training modules to include some of the Renal Palliative Care Model of Care, specifically for WA.
- Use self directed packages. Queensland has developed extensive self directed packages for residential care and another for nurses and care workers. These include DVDs:
  1. A palliative approach in residential care – self directed learning packages.
  2. Journey in palliative care for children and teenagers.

These may be used as they are or adaptation options can be explored

## 12.5 Ongoing education

- refresher study sessions
- journal clubs
- regular forums for discussion and symposia would be part of the overall renal palliative care service in order to promote discussion and feedback. The program would aim to foster strong relationships with clinical leaders through regular interaction and training (St George Hospital NSW Renal Palliative Care program).

<http://stgrenal.med.unsw.edu.au/StGRenalWeb.nsf/page/Palliative%20Care%20Section>

## 13. Extension of services into rural and remote Western Australia

The Rural Palliative Care Model in Western Australia<sup>36</sup> provides a framework for improving access to specialist palliative care across rural and remote regions and supplements the Palliative Care Model of Care.<sup>3</sup> The key elements and principles of the Palliative Care Model of Care remain the foundations for the rural model:

- Provides services for patients with life limiting illness, regardless of diagnoses.
- Addresses the palliative care needs of patients and their families during the illness trajectory.
- Delivers care in any setting – hospital, palliative care unit, residential care or home.
- Identifies partnerships between specialist palliative care services and primary care providers.

All seven WA Country Health Services (WACHS) regions have established Regional Palliative Care Services with a Palliative Care Nurse Manager/Coordinator leading a core speciality team inclusive of a social worker, clinical nurses, an administration assistant and (or with access to) an Aboriginal health worker. The teams provide coordination, clinical leadership and consultancy in palliative care and link with specialist palliative care physicians who provide visits and/or support (Appendix 1).

Links with renal teams are already established in some areas, for example the Kimberley where joint renal and palliative care case conferencing meetings are held regularly. The Renal Palliative Care Pathway provides an opportunity to formalise the integration of palliative care into ESKD throughout the regions by enabling a collaborative approach to care.

The Regional Palliative Care Services will be the point of contact for renal patient referrals to provide support and advice with end of life decision making, symptom management, specialist palliative care physician consultation, end of life care, and the provision of culturally appropriate palliative care. This may initially be done on a case by case basis with a view to establishing joint renal and palliative care clinics and or case conferencing meetings face to face or via teleconferencing facilities in the future.

A Referral Pathway to guide access to rural palliative care services is currently under development.

### 13.1 Pilot study

It is recommended that a pilot study be undertaken in one of the regional areas to demonstrate that the Renal Palliative Care Pathway can be used to improve quality of life and provide cost effective management for ESKD patients in rural and remote WA.

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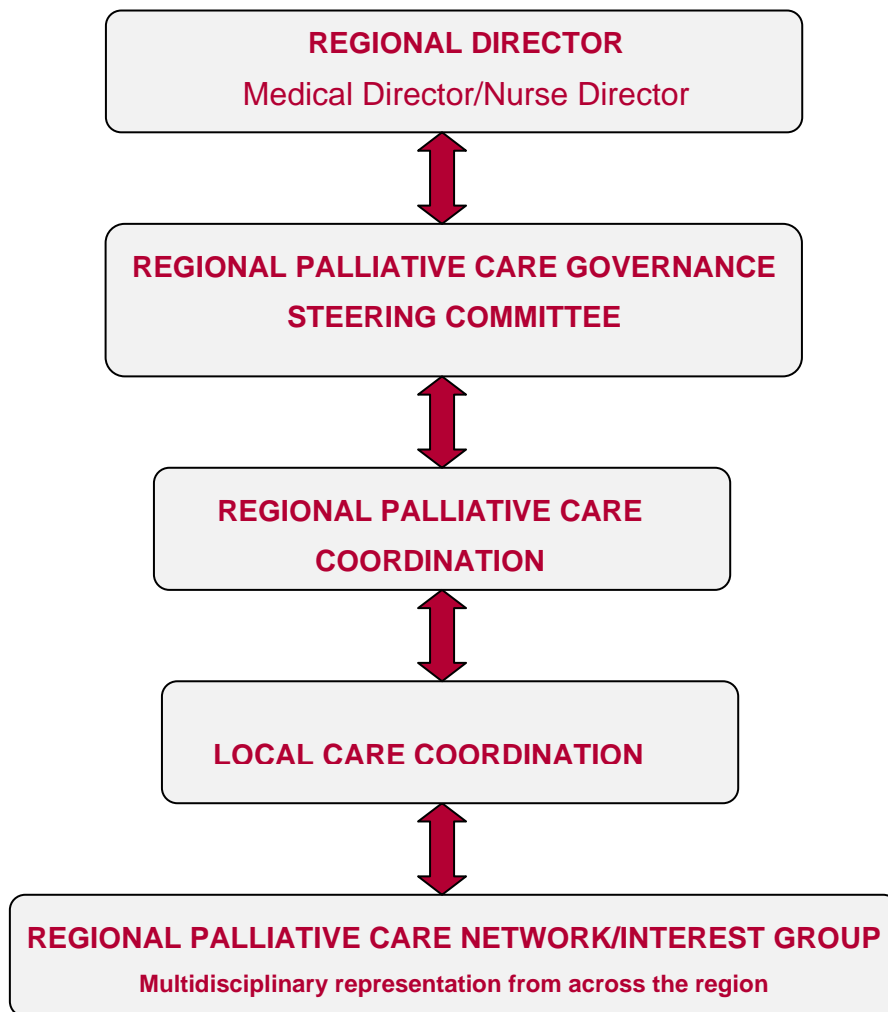
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## 15. Appendices

### Appendix 1: Regional Palliative Care Framework



Source: Rural Palliative Care Model in Western Australia.<sup>36</sup>



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