



# **PALLIATIVE CARE FOR CHRONIC AND END-STAGE KIDNEY DISEASE**



**Position Statement**

This is a joint position statement from Palliative Care Australia (PCA) and Kidney Health Australia.

**Palliative Care Australia** is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.

**Kidney Health Australia** is the national peak body for kidney disease. It has been incorporated since 1968. Kidney Health Australia has the vision 'to save and improve the lives of Australians affected by kidney disease'. Their mission is 'to promote good kidney health through education, advocacy, research and support'.

### PCA & Kidney Health Australia believe:

- Palliative care<sup>1</sup> should be available to all people diagnosed with CKD/ESKD, who need and choose it.
- People with CKD/ESKD, their family and carer/s should have access to palliative support from a multidisciplinary, collaborative team that can be used in conjunction with renal supportive care strategies, dialysis and transplantation in order to provide the best quality of life possible for each individual.
- There should be effective referral and communication pathways between renal health professionals, general practitioners and palliative care teams in order to provide streamlined care and effective use of health and human resources.
- Care should be person centred to enable a focus on individual unique perceptions of what constitutes quality of life. The person, their family and carer/s are entitled to make informed decisions regarding treatment pathways.
- The cultural, spiritual and religious beliefs of people with CKD/ESKD must be determined and respected. This is an essential element in supporting quality of life for the person with CKD/ESKD. An individual's beliefs may inform or determine decision making, including whether to commence, continue or withdraw from dialysis.
- All renal and primary health care professionals should be educated and practise at a level appropriate to their position to provide accurate advice and information to people with CKD/ESKD, their families and carer/s in order to ensure informed and structured shared decision making.
- Every person with ESKD should have their kidney disease symptom burden assessed using validated and standardised instruments and assessment tools every 3 to 6 months.
- Advance Care Planning and Advance Care Directives should be a standard part of the care-plan for people with ESKD.
- Health professionals, patients and carer/s need to be provided with accurate information and education about palliative care and renal disease.

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<sup>1</sup> A supportive approach that aspires to improve the quality of life of a person and their families facing a terminal illness, in accordance to the person's wishes and through the prevention and relief of suffering by early identification and treatment of pain and other problems, physical, psychosocial and spiritual. (*World Health Organisation*)

## PCA & Kidney Health Australia call for:

- Improved access to palliative care services for people with CKD/ESKD, their family and carer/s.
- Education for renal health professionals and general practitioners about the articulated pathways and referral systems, in all jurisdictions, to palliative care services for people with CKD/ESKD.
- Up-skilling and appointment of specialist doctors or nurse practitioners to improve access to treatment and palliative care services for remote, rural and regional patients, particularly for Aboriginal and Torres Strait Islander peoples.
- A central national resource point for written, digital information and education for patients, carers and health professionals on palliative care associated with kidney disease.
- Education and ongoing support for renal specialists, renal medicine trainees and general practitioners by palliative care specialists on the benefits of a palliative approach for people with CKD/ESKD, their families and carer/s.
- National implementation of a validated tool to objectively measure the symptom burden associated with ESKD with an associated quality improvement indicator, such as the Palliative Outcome Scale – Symptoms Renal (POS-S Renal).<sup>2</sup>
- Targeted implementation strategies to promote advance care planning amongst renal health professionals, people with CKD/ESKD, their families and carer/s.
- More accessible information and education for health professionals, patients, their family and carer/s on palliative care and kidney disease.
- A national project/research to evaluate which delivery model(s) of palliative care for someone with CKD/ESKD are cost and resource effective and enhance the patient's quality of life.

## Background:

### The relationship between Chronic Kidney Disease and Palliative Care

Chronic Kidney Disease (CKD) becomes life-limiting when it progresses to stage 5<sup>3</sup> and is known as End Stage Kidney Disease (ESKD). Treatment options include renal replacement therapy in the form of kidney transplant, regular dialysis (which may be either haemodialysis or peritoneal dialysis) and supportive care. Supportive care is a program that demonstrates a palliative approach, involving elements such as medications, diet, psychosocial support and recognition that the disease is life-limiting.

It is estimated that 5,000 new people present annually with ESKD. Of these patients, approximately half choose to commence renal replacement therapy, and half do not receive dialysis for a variety of reasons. These people should have access to supportive care. Around 20% of patients who initially choose renal replacement therapy change to palliative care at a later date.<sup>4</sup> There is currently a 4% increase in ESKD prevalence per annum, with 11,446 people receiving dialysis treatment in December 2012.<sup>2</sup>

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<sup>2</sup> The POS measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training. The Palliative care Outcome Scale - Symptoms (POS-S) is an additional, condition specific scale Accessed from <http://pos-pal.org/>

<sup>3</sup> End-stage kidney disease (ESKD) is the most severe form of chronic kidney disease, also known as Stage 5 chronic kidney disease (CKD). (*Australian Institute of Health and Welfare*)

<sup>4</sup> ANZDATA Australia and New Zealand registry report(2013) [www.anzdata.org.au](http://www.anzdata.org.au)

Despite technological and medical improvements, renal replacement therapy has its limitations. Transplantation is not suitable for many people. The transplants have a limited lifespan and the associated medications may cause severe side-effects, including a 2.5 times greater risk of cancer.<sup>2</sup> Similarly, dialysis fails to provide a cure for kidney disease, offers limited symptom reduction, and incurs significant treatment burdens.<sup>5</sup>

Palliative care is a valuable part of treatment and support for people with CKD/ESKD. Whether carrying out dialysis or opting for a supportive non-dialysis pathway, palliative care teams aim to provide holistic, person centred supportive care for the person, their family and carer/s.

## Current State

In Australia Kidney Failure:

- As a principal or additional diagnosis is the 3rd most common cause of palliative care-related hospital separations (behind secondary cancer and lung cancer)
- As the principal diagnosis accounts for 36% of all palliative care patient deaths.<sup>6</sup>

The Commonwealth palliative care strategy, 2010, *Supporting Australians to Live Well at the End of Life*, highlights four key areas for change; awareness and understanding, appropriateness and effectiveness, leadership and governance, capacity and capability. Renal palliative care services currently have many gaps compared to the standards in this strategy.<sup>7</sup>

## Appropriateness and Effectiveness

Patients with Chronic Kidney Disease and End-Stage Kidney Disease are amongst the most symptomatic of any chronic disease group, with an average seven symptoms affecting their daily life.<sup>8</sup> Symptoms can include itching, fatigue, depression, constipation, insomnia, nausea, vomiting, shortness of breath and pain.<sup>9</sup> These symptoms are frequently under-diagnosed or inadequately treated which reduces the individual's quality of life. Symptom assessment tools have been modified for renal patients<sup>10</sup> but there is limited uptake of formal clinical assessment throughout Australia.

Occasional renal units have collaborated with palliative care services to commence joint renal/palliative care clinics, policies and care pathways.<sup>11</sup> This has led to other States independently commencing development of models of care or pilot projects to determine evidence based pathways for supportive and palliative care.<sup>12</sup> Referral pathways within these structures vary by jurisdiction and are reliant on the expertise and focus of individual health care professionals or the availability of services. There are no national guidelines to indicate appropriate referral pathways and the associated rationale.

## Capacity and Capability

It is important to take note that people with ESKD are likely to have already established long and close relationships with their renal treatment team. There is increasing recognition and awareness among renal health professionals that dialysing those with multiple co-morbidities, poor functional status and increasing dependence may be burdensome, adversely affecting (and not necessarily extending) their quality of life.<sup>8</sup> The workforce for delivery of palliative care services should be led by palliative care specialist staff in accordance with the renal treatment team.

Renal health professionals need to be provided with further opportunities to partake in education and training in the palliative approach. Regular symptom assessments need to be made, and referral opportunities with specialists should be utilised to ensure all facets of care are maximised. The health

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5 Masterson, R., & Foote, C. "Perspective – the issues surrounding end-stage kidney disease and dialysis in the elderly and those with co-morbidities" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.403

6 Australian Institute of Health and Welfare, "Palliative care services in Australia" HWI 123, Canberra: AIHW; 2013.

7 Commonwealth of Australia, National Palliative care strategy, 2010

8 Murphy, E., Murtagh, F., Carey, I., Sheerin, N. "Understanding Symptoms in Patients with Advanced Chronic Kidney Disease Managed without Dialysis: Use of a Short Patient-Completed Assessment Tool" *Nephron Clinical Practice* 2009;111 pp. 74–80

9 Phipps, L. et al "Educational Needs in Supportive and End-of-life Care" *Nephrology*

10 Cicely Saunders Institute, "Palliative care Outcome Scale-Symptoms" POS-S , 2014 <http://www.csi.kcl.ac.uk/pos-s.html>

11 St. George Hospital Renal and hypertension unit (2014). Palliative care viewed at

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

12 Western Australia Department of Health, "Pathway for renal palliative care services", 2012.

professionals should include those from allied health, such as social workers and dieticians. The goal is to ensure a workforce that is resource effective whilst collaborating confidently and capably in the palliative management of this chronic and life limiting condition.

## Awareness and Understanding

In order to achieve the best quality of life for the person with CKD/ESKD, health care professionals need to communicate with and properly inform, understand and support the person, their family and carer/s. By raising awareness and providing information and support, the person, their family and carer/s will be able to make informed decisions on their future care, while being aware of, and having access to relevant support networks.

Shared decision making is recognised as the gold standard and in 2013 the Australian, *My Kidneys, My Choice Decision Aid*, was developed as part of a Kidney Health Australia Commonwealth funded project to support this process.<sup>13</sup> The treatment option of supportive care is included to ensure that all people with CKD are made aware of this option. Integration of the decision aid into practice is currently underway around Australia.

Cultural and religious beliefs are likely to impact upon or determine a patient's view on medical decision making, including whether to commence, continue or withdraw from dialysis.<sup>14</sup> It is therefore critical when aiming to achieve good quality of life for the person, their family and carer/s that their beliefs and culture are ascertained and respected. Rates of advance care planning uptake in renal units have not been determined but are estimated to be low. Palliative care standards and procedures promote the use of advance care planning so that the wishes and preferences of the person, their family and carer/s can determine treatment in response to any unexpected events.<sup>15</sup>

The highest incidence rates of CKD and ESKD in Australia occur within remote, regional and Indigenous communities. Although not all Indigenous groups are affected equally by ESKD, there are some communities where the rates are approximately twenty times higher than the national figure. This has accelerated in the past few years in conjunction with co-existing conditions of type II diabetes and ischaemic heart disease, often due to rapidly changing lifestyles, poor diet, relative poverty and high levels of disadvantage.<sup>16</sup>

Despite these challenges, access to specialist palliative care services and information about palliative care in rural and remote communities is limited for both patients and health professionals.<sup>17</sup> Palliative care in rural and remote areas is generally delivered by primary care physicians and community nurses and not palliative care specialists. The limited support, education and information provided to these health professionals make the management of palliative care and renal support difficult in areas that have a substantial prevalence of CKD and ESKD.

## Leadership and Governance

Re-allocation of resources may be required for implementation of renal-palliative care pathways and evaluation of different models is critical. There are many excellent jurisdictional documents and strategies for general implementation of advance care planning.<sup>18</sup> Despite this, local implementation is reported to be low, with no reporting of quality indicators or monitoring of uptake. There is a need for renal health professionals to partake in the monitoring and reporting of quality indicators of renal palliative/supportive care through validated programs, such as the National Standards and Assessment Program (NSAP).

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13 Kidney Health Australia, "My Kidneys, My Choice" *Decision Aid*. [www.homedialysis.org.au/choosing](http://www.homedialysis.org.au/choosing)

14 Brennan, F. "Holistic Palliative Care Approach – Physical, Spiritual, Religious and Psychological Needs" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.421

15 Palliative Care Australia, *The Standards for Providing Quality Palliative Care for All Australians*, 4th Edition, 2005

16 Sajiv, C., "Cultural Considerations when providing care to Aboriginal and Torres Strait Islanders option for conservative care" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.430

17 May, S., "Issues and Models of Renal Supportive care in Rural Areas" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.435

18 NSW Ministry of Health "Advanced planning for quality care at the end of life action plan 2013-2018" 2013 [www.http://www.health.nsw.gov.au/patients/acp/Publications/acp-plan-2013-2018.pdf](http://www.health.nsw.gov.au/patients/acp/Publications/acp-plan-2013-2018.pdf)