

Kidney supportive care: every nephrologist's business



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The concept of kidney supportive care (KSC) grew from an increasingly recognized need to provide treatment directed at the *quality* as well as the *quantity* of life of people living with chronic kidney disease (CKD). KSC attends to the lowered well-being and multiple—often severe—symptoms associated with CKD, which can be overlooked and stay unaddressed with disease-focused care in busy clinical settings.

We represent an international group, heavily involved in the development of contemporary KSC. We reflect on the available evidence and our experiences of researching, establishing, developing, and quality assuring KSC services across geographic and resource settings. Different nephrologists are at different stages of accepting and learning about what KSC and conservative kidney management (CKM) entail. We acknowledge and applaud those who provide most components of KSC most of the time. Meanwhile, we believe that KSC has yet to become part of mainstream nephrology. A recent Global Kidney Health Atlas survey found extensive variation in how CKM and KSC were defined, and what and how much care was provided.¹

A separate survey of 114 kidney services across Australia, New Zealand, and the United Kingdom showed that a third do not provide KSC services, and even where a service is available, this often does not involve a nephrologist.² It is our opinion that (i) KSC must be considered an essential part of nephrology services, universally accessible to all people under our care; (ii) clinical skills in KSC should become mandated core competencies of all nephrology training programs; and (iii) optimum and proportionate care will ensue with KSC services integrated across the CKD trajectory. We advocate for acceptance and awareness of KSC in general, and CKM in particular. We promote recent guidelines and educational opportunities in this field, particularly the International Society of Nephrology (ISN) curriculum (<https://academy.theisn.org/products/kidney-supportive-care-and-conservative-kidney-management-curriculum>).

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What is KSC?

KSC is defined as “an approach that improves the quality of life for people with all stages of CKD, both those receiving and not receiving kidney replacement therapy (KRT), and their families, 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.”³ This description draws on the World Health Organization definition of palliative care, reflecting how palliative care principles and practices can be applied for all people living with CKD. Consistent with this approach, KSC has a critical focus on shared decision-making as well as the core principles of management of physical, psychological, social, practical, and spiritual concerns across the disease course—from diagnosis, up to and including end-of-life-care and bereavement. KSC programs can be evaluated by measuring the success in achieving these domains, and there are several validated tools available to help do so (see Table 1).

Where does CKM fit in?

It would be erroneous for the terms KSC and CKM to be used interchangeably. The ISN has recently published international consensus definitions for both.³ Although KSC denotes palliative care for *all* people living with CKD, CKM is care for those with kidney failure, for whom KRT is not planned nor expected to be used. Treatments aimed at delaying the progression of kidney disease can continue, if aligned with the patient's priorities. However, symptom control, dignity, and comfort are typically prioritized, making KSC the core of CKM. CKM should be available for those who make a shared decision not to start KRT and for others who are unable to access KRT—*choice-restricted CKM*.

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Table 1 | Some suggestions to facilitate the integration of KSC into every nephrologist's practice

Variable	What you, the nephrologist, can do	What local kidney services and national programs can do
1. Making KSC the responsibility of every nephrologist	Ask patients about their symptoms and about what is important to them. Embrace KSC as permission to prioritize supportive care aspects, even when the system or your training have historically prioritized others.	Document patients' needs—assess symptoms, quality of life, and uptake of advance care plans. Invariably, there will be a high symptom burden, impaired quality of life, and a poor uptake of advance care plans. Combined, this shows the need for KSC service provision. Various validated tools are available to assess symptoms (e.g., ESAS-r:Renal, iPOS-Renal), quality of life (e.g., EQ-5D), and frailty (e.g., Edmonton Frail Scale). These are addressed in the ISN curriculum.
	Do not wait for funding, start with “the willing.” Having 1 or 2 nephrologists in the department who are “champions” for KSC will ensure good modeling and training of others. Address resistance and consider where it is coming from.	Develop systematic local approaches to KSC (e.g., routine symptom screening using validated instruments). Have open discussions and include those who are resistant in the planning.
	Through open discussion and sharing of evidence, help your colleagues and patients to appreciate the limitations of dialysis and transplantation—wonderful technologies as these are—to control all symptoms. Use the “surprise question” to initiate prognostication discussions and help bring the focus on important domains, such as symptom burden, quality of life, and functional status, and embrace the proactive and supportive nature of KSC and CKM.	Apply pressure to funding structures to recognize provision of KSC and CKM as being just as important in CKD and KF management as dialysis or transplantation.
2. Equipping nephrologists and those in training with the skills and knowledge to provide KSC	Demonstrate the process around KSC and CKM by ensuring that all clinicians involved in the patient's care, and the family, are “on the same page” through goal-oriented shared decision-making processes. In units where this works well, this responsibility is embraced by the patient's nephrologist, commonly supported by nursing staff involved in the KSC team. Ensure KSC and CKM are part of the formal and situational learning of every trainee under your guidance. Present cases locally and broadly. Role model the practice of KSC so trainees and colleagues see that this is part of the art of nephrology. For example, when expecting to discuss dialysis discontinuation with a patient, take a trainee with you. Examine for KSC skills in internal assessments.	Initiate training programs in specialized communication skills, such as Nephrotalk, to enable goal-oriented shared decision-making. Ensure that trainees are exposed to the literature, skills, and practice of KSC and CKM. This should be supplemented with expert international teaching via the ISN Academy (https://academy.theisn.org/products/kidney-supportive-care-and-conservative-kidney-management-curriculum), KDIGO guidelines (https://kdigo.org/conferences/supportivecare/), and other national societies. Ensure qualifying examinations include KSC skills.
	Trainees can do this work too; where they are activated and encouraged to provide it, they can help to propagate the cultural shift toward KSC being part of what it is to do nephrology. This will develop the skills of current nephrologists and a whole new generation of skilled practitioners, some of whom will choose to dual train in nephrology and palliative care.	Form strong links with your local palliative care services. Apply validated symptom burden tools to document burden. This will help to identify where and when specialist palliative care input is needed and will upskill your palliative care teams in the unique needs of people with KF.
3. Ensuring CKM is viewed as an evidence-based and legitimate option for KF management	Offer CKM as one of the options to all people at risk of developing or with kidney failure. Provide them with unbiased information regarding what their available treatments will involve and what we know about the length and quality of life that they are likely to achieve. Providing the option for CKM is an important part of the legal process of consent for KRT. Have scientific clarity when conversing on this domain. Help patients decide between their options based on what is important to them, and continue to support them, whatever decision they make.	Unavailability of KSC services perpetuates the idea of “dialysis or nothing” and means nephrologists will lack expertise in CKM delivery. Local services should strive to provide CKM. National programs should ensure quality of CKM care, reflecting the core components set out by the ISN. Encourage research on KSC/CKM domains.

Table 1 | (Continued) **Some suggestions to facilitate the integration of KSC into every nephrologist’s practice**

Variable	What you, the nephrologist, can do	What local kidney services and national programs can do
4. Delivering multidisciplinary KSC	Conduct a series of tutorials to the MDT, dialysis technologists, and nephrology colleagues based on the ISN KSC/CKM curriculum.	Ensure you have a well-trained MDT—meet often and debrief, especially on what is being achieved at different levels to discern utility and futility of ongoing care processes. Nurses are often the core of such MDTs.
	Introduce KSC discussions into existing MDT meetings. Discussion of patients already presented at MDT meetings will allow identification of other patients who need KSC support.	“Spread the word” through presentations at departmental meetings, medical grand rounds, symposia, and masterclasses. Seed the concepts within the local professional community by publishing institution-based or multicentric research in KSC/CKM.

CKD, chronic kidney disease; CKM, conservative kidney management; EQ-5D, EuroQol 5-dimension; ESAS-r:Renal, Edmonton Symptom Assessment System–Revised: Renal; iPOS-Renal, Integrated Palliative Outcome Score Renal Survey; ISN, International Society of Nephrology; KDIGO, Kidney Disease: Improving Global Outcomes; KF, kidney failure; KRT, kidney replacement therapy; KSC, kidney supportive care; MDT, multidisciplinary team.

Access to CKM is not universal in either of these settings. Analysis of Global Kidney Health Atlas 2023 data showed that CKM is offered in some form in 61% of countries.¹ Yet, the detailed reports from these countries indicate incomplete delivery of the essential core components of KSC; for example, only 16% of low-income countries and 51% of high-income countries had more than half of nephrology centers using validated symptom screening tools, meaning patients’ symptom burden will often be underestimated. They report inadequate access to nonmorphine opioids for managing pain, or to gabapentinoids for managing restless legs syndrome and pruritus.

Why has it taken so long for nephrology to embrace KSC?
KSC and CKM have been in development for ≈20 years. However, guidelines and curricula have only begun to define, promote, and detail their essential components in recent years. [Table 2](#) highlights some of the reasons why uptake has been slow, and arguments for why this must change.

How can the international nephrology community help develop KSC?
First, nephrologists already practicing KSC need to be exemplary role models for their peers and trainees, demonstrating how to talk to families and patients about symptom burden, quality of life, carer stress, and a range of existential issues. In this way, KSC is seen as it should be—a normal part of day-to-day nephrology practice. We are fortunate to have a new generation of nephrology trainees who are embracing KSC, and their best way of learning is to see this practice modeled by their seniors.

Second, the ISN has embraced KSC and CKM as integral components of kidney care.³ This has included dedicated sessions at the World Congress of Nephrology 2024 in Argentina and World Congress of Nephrology’25 in India and, importantly, the development of an online curriculum on KSC/CKM hosted by the ISN Academy (<https://academy.theisn.org/products/kidney-supportive-care-and-conservative-kidney-management-curriculum>). This open-access curriculum explains the meaning and applicability of KSC and CKM and provides clear educational tools to help in CKM decision-making and in the delivery of KSC, such as symptom management and advance care planning. The course development involved contributors from across regions and takes into consideration diverse cultural perspectives and disparate resource settings.

Dialysis can be perceived as *the* life-prolonging intervention for people with kidney failure, and getting all nephrologists to embrace CKM may be challenging. Recent Kidney Disease: Improving Global Outcomes CKD guidelines (section 5.5) promote CKM as part of integrated care (<https://kdigo.org/wp-content/uploads/2017/02/KDIGO-2024-CKD-Guideline-Executive-Summary.pdf>). Nephrologists must accept that longevity is not always the highest priority for those living with kidney failure. We must recognize and communicate that the survival benefit of dialysis may be small for older people and those living with multiple long-term conditions and frailty.⁶ We must resist oversimplifying decisions between dialysis and CKM as between providing treatment and “doing nothing.” KSC services that ensure good quality of life and support must be available to patients and their families who are considering CKM.

Table 2 | Some reasons why KSC has yet to be integrated into everyday routine kidney care and arguments for why this must change

Reasons	Rebuttals
Nephrology evolved as the art of treating kidney disease to prevent kidney failure, and of treating kidney failure with KRT. Busy nephrologists may not relate to their role as going beyond kidney parameters, toward the holistic comfort and quality of life of the <i>person</i> with the kidney disease.	Holding the keys to KRT means that nephrologists must also know when it is best to recommend KSC or the transitions to CKM instead, and when the time to discontinue KRT has come. We need skills to prognosticate, to listen, and to counsel people with kidney failure, their families, and our colleagues through these difficult decisions—and we must expertly support our patients through their lives with kidney failure, however it is treated. These are not separate domains from KRT planning and provision—they are part of the art.
A detailed and researched appreciation of the symptom burden of people with CKD and those on KRT was not forthcoming until recent years, perpetuating beliefs that CKD/KRT are painless, and largely asymptomatic until late in its course.	People with CKD have complex health care needs with a high symptom burden, including pain, throughout their illness trajectory. ⁴ These symptoms correlate negatively with quality and length of life. ⁵
Nephrologists consider themselves to already have the expertise to manage the issues that KSC relates to. There is a long-held notion that starting dialysis, providing more dialysis, or ensuring a better “mathematical” delivery of dialysis (Kt/V) can alleviate the symptoms and distresses of kidney failure and KRT.	The evidence to support intensified dialysis for those with classic uremic symptoms is mixed. As one example, analysis of DOPPS data has found no association between itch and phosphate, calcium, calcium-phosphate product, parathyroid hormone, Kt/V, or use of hemodiafiltration. Meanwhile, many living with CKD are older, and living with multiple long-term conditions. For these people, symptoms and quality of life may not be primarily driven by kidney disease, and treatment burden can contribute negatively. In observational studies, there is no strong evidence that symptom control is superior for those who initiate dialysis. ⁶
A lack of evidence, standards, and guidelines for symptom management has maintained the lesser focus on these aspects of care, compared with conventional quality-assured aspects, such as hemoglobin concentration or blood pressure.	Although evidence is still awaited for the management of certain symptoms, there is now a solid body of evidence on CKD-associated pruritus, international guidelines on the management of pain and restless legs syndrome, and decades of experience in extrapolating the management of specific symptoms from the general population—in many ways comparable to the evidence base on which much of nephrology is practiced. Nephrologists now have these tools (e.g., ISN curriculum) to upskill in all aspects of KSC.
Palliative care (and by extension KSC) has long been regarded by patients, the public, and many physicians, as care that is relevant only for people in their last days or weeks of life.	This fails to appreciate the benefits that patients and families can derive when these skills are adopted early in the trajectory of illness. People receiving CKM can survive well past 12 months with controlled symptoms and maintained quality of life when receiving KSC. Meanwhile, many people receiving KRT stand to benefit from KSC across their disease course.
Nephrologists do not have the time to add KSC to an already busy schedule.	Perhaps it is time to adjust our approach as to what it is to “do nephrology.” Some nephrology consultations may need to prioritize aspects of KSC, whereas others for the same patient may continue to prioritize more urgent biochemical or other clinical concerns. These approaches are synergistic and can be accommodated over time, leading to a truly holistic approach of care by every nephrologist, whether they are managing people pre-KRT, on KRT, or receiving CKM.

CKD, chronic kidney disease; CKM, conservative kidney management; DOPPS, Dialysis Outcomes and Practice Pattern Study; ISN, International Society of Nephrology; K, dialysis clearance of urea; KRT, kidney replacement therapy; KSC, kidney supportive care; t, dialysis time; V, volume of distribution of urea.

What are the changes required to ensure integration of KSC and CKM into nephrology practice?

- (i) KSC is not a separate entity and should not be limited to a few centers. Every nephrologist caring for patients should accept the responsibility of providing this essential service. Many already do this, but further progress is needed, and we can all continue to upskill.
- (ii) Nephrology training regulatory bodies should include the basic skills and knowledge for KSC as core competencies and integrate these into qualifying examinations.

- (iii) CKM should be viewed and be shared with patients and families, as an evidence-based and legitimate option for kidney failure management, alongside KRT.
- (iv) As with all aspects of kidney care, KSC is best delivered by multidisciplinary teams. Although the nephrologist has responsibility to ensure comprehensive KSC, and should have at least basic training in this field, multidisciplinary teams should leverage the various expertise of individual team members, particularly nursing staff. At times, this will also include specialist palliative care comanagement.

We believe that these changes may be achieved by embarking on the steps outlined in [Table 1](#).

The long-recognized palliative care needs of people living and dying with kidney failure require consideration as part of nephrology care, and the ISN continues to work to improve global access to these vital aspects of integrated kidney care. We know what the essential components of KSC and CKM include and need to work out how to ensure the international nephrology community can deliver them. We find ourselves at a pivotal stage, where we all should develop an awareness of how KSC and CKM is part of our practice and similarly integral toward research and teaching academics in nephrology. We hope that this editorial signposts how individuals and services can make the progress that is needed. The quality-of-life benefits for those living with CKD are enormous once we succeed in achieving this.

DISCLOSURE

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