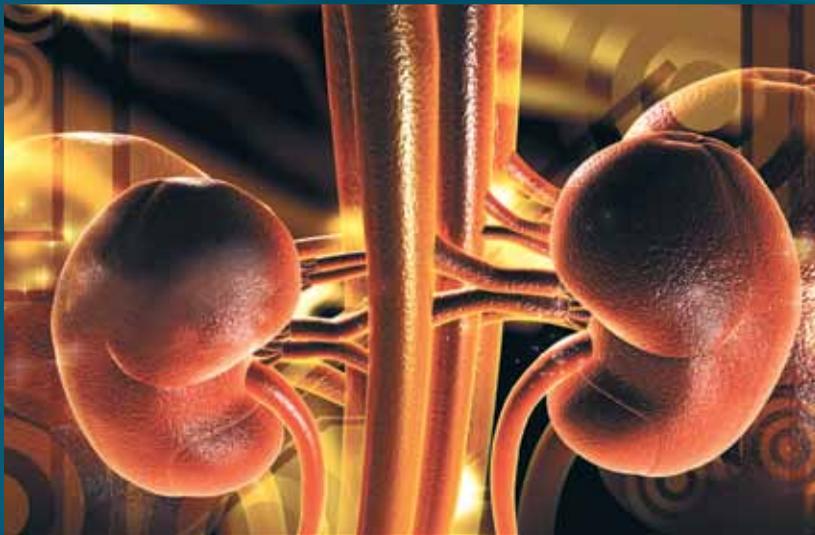


# Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline

*Second Edition*



**RPA**

Renal Physicians Association

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# About the Renal Physicians Association

[www.renalmd.org](http://www.renalmd.org)

Since 1973 the Renal Physicians Association (RPA) has been dedicated to representing and serving nephrology practitioners in their pursuit and delivery of quality renal health care. RPA is a non-profit 501c6 national nephrology specialty medical association with over 4,000 members serving kidney patients. Our programs focus in the areas of practice management, public policy and quality patient care. We are the voice of nephrology practice and a committed advocate to the renal community, payers and federal policy makers. Our membership is comprised of physicians, physician assistants, advanced nurse practitioners and practice managers. These nephrology healthcare providers are engaged in diverse activities, including the practice of medicine, teaching, research, administration and they are devoted to improving the care of patients with kidney disease and related disorders. We provide timely and relevant programs along with current nephrology tools and resources to make certain our members maintain their highest level of professional satisfaction. To obtain more information about RPA or to become a member please contact us at (301) 468-3515 or by email at [rpa@renalmd.org](mailto:rpa@renalmd.org).

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# Recommendation Summary

To develop their recommendations, the RPA Working Group used a priori analytic frameworks regarding decisions to withhold or withdraw dialysis in adult and pediatric patients with AKI, CKD, and ESRD. Systematic literature reviews were conducted to address pre-specified questions derived from the frameworks. The research evidence, case and statutory law, and ethical principles were used by the Working Group in the formulation of their recommendations.

## Adult Patients

### Establishing a Shared Decision-Making Relationship

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#### Recommendation No. 1

#### **Develop a physician-patient relationship for shared decision-making.**

Shared decision-making is the recognized preferred model for medical decision-making because it addresses the ethical need to fully inform patients about the risks and benefits of treatments, as well as the need to ensure that patients' values and preferences play a prominent role. Because of the number and complexity of decisions involved in treating kidney failure, a shared decision-making relationship is particularly important for patients with acute kidney injury (AKI); stage 4 and 5 chronic kidney disease (CKD); and stage 5 CKD requiring dialysis end-stage renal disease (ESRD). Participants in shared decision-making should involve at a minimum the patient and the physician. In addition, patients should identify and include a person who could serve as their decision-maker in the event they lose decision-making capacity. If a patient lacks decision-making capacity, decisions should involve the person legally authorized to make health care decisions on behalf of the incapacitated patient. This person is often (though not always) a family member and will be called "the legal agent" in the remainder of this document (see **Section 10: Glossary** for a full description ). With the patient's consent, shared decision-making may include family members or friends and other members of the health care team.



## Informing Patients

#### Recommendation No. 2

#### **Fully inform AKI, stage 4 and 5 CKD, and ESRD patients about their diagnosis, prognosis, and all treatment options.**

In the setting of critical illness many patients with CKD will require urgent dialysis and the vast majority of patients with AKI will have multiple medical problems, in addition to kidney failure. The concept of shared decision-making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments. For example, a decision to withhold dialysis in a patient agreeing to and receiving multiple other forms of life-sustaining therapy could represent discordant treatment in the same way that offering dialysis to a patient who has decided to forgo other forms of life-sustaining therapy might be inappropriate. Intensive care physicians need to be included in shared decision-making for kidney patients in the intensive care unit (ICU).

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For ESRD patients, the shared decision-making options include: 1) available dialysis modalities and kidney transplantation if applicable; 2) not starting dialysis and continuing medical management; 3) a time-limited trial of dialysis, and 4) stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary. The renal care team, in conjunction with the primary care physician, should insure that the patient or legal agent understands the benefits and burdens of dialysis and the consequences of not starting or stopping dialysis. Research studies have identified a population of chronic kidney disease patients for whom the prognosis is particularly poor. This population has been found to include patients with two or more of the following characteristics: 1) elderly (defined by research studies identifying poor outcomes in patients who are age 75 years and older); 2) patients with high comorbidity scores (e.g., modified Charlson Comorbidity Index score of 8 or greater); 3) marked functional impairment (e.g., Karnofsky Performance Status Scale score of less than 40); and 4) severe chronic malnutrition (e.g., serum albumin level less than 2.5 g/dL using the bromeresol green method). Patients in this population should be informed that dialysis may not confer a survival advantage or improve functional status over medical management without dialysis and that dialysis entails significant burdens that may detract from their quality of life.

### **Recommendation No. 3**

**Give all patients with AKI, stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition.**

To facilitate informed decisions about starting dialysis for AKI, stage 5 CKD, or ESRD, all patients should have their prognosis estimated and discussed, with the realization that the ability to predict survival in the individual patient is limited. Depending on the setting, a primary care physician, intensivist, or nephrologist who is familiar with estimating and communicating prognosis should conduct these discussions (see **Recommendation No. 10** for communication strategies). For patients with ESRD, the “surprise” question “Would I be surprised if this patient died in the next year?” can be used together with known risk factors for poor prognosis: age, comorbidities, severe malnutrition, and poor functional status. For patients with stage 5 CKD pre-dialysis, the estimate of prognosis should be discussed with the patient or legal agent, patient’s family, and among the medical team members to develop a consensus on the goals of care and whether dialysis or active medical management without dialysis should be used to best achieve these goals. These discussions should occur as early as possible in the course of the patient’s kidney disease and continue as the kidney disease progresses. For ESRD patients on dialysis who experience major complications that may substantially reduce survival or quality of life, it is appropriate to reassess treatment goals, including consideration of withdrawal from dialysis.

## Facilitating Advance Care Planning

### Recommendation No. 4

#### **Institute advance care planning.**

The purpose of advance care planning is to help the patient understand his/her condition, identify his/her goals for care, and prepare for the decisions that may have to be made as the condition progresses over time. For chronic dialysis patients, the interdisciplinary renal care team should encourage patient-family discussion and advance care planning and include advance care planning in the overall plan of care for each individual patient (see **Section 10: Glossary** for definition of renal care team). The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be strongly encouraged while they have capacity to talk to their legal agents to ensure that the legal agent knows the patient's wishes and agrees to make decisions according to these wishes.

The renal care team should attempt to obtain written advance directives from all dialysis patients. Where legally accepted, Physician Orders for Life-Sustaining Treatment (POLST) or similar state-specific forms, also should be completed as part of the advance care planning process. At a minimum, each dialysis patient should be asked to designate a legal agent in a state-specific advance directive. Advance directives should be honored by dialysis centers, nephrologists, and other nephrology clinicians except possibly in situations in which the advance directive requests treatment contrary to the standard of care (see **Recommendation No. 8** on conflict resolution).



## Making a Decision to Not Initiate or to Discontinue Dialysis

### Recommendation No. 5\*

#### **If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD, or ESRD in certain, well-defined situations.**

These situations include the following:

- Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued.
- Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive.
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued.
- Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.

\*Medical management incorporating palliative care is an integral part of the decision to forgo dialysis in AKI, CKD, or ESRD, and attention to patient comfort and quality of life while dying should be addressed directly or managed by palliative care consultation and referral to a hospice program (see **Recommendation No. 9** on palliative care services).

# Recommendation Summary

## Recommendation No. 6

**Consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.**

Included in these categories of patients are the following:

- Those whose medical condition precludes the technical process of dialysis because the patient is unable to cooperate (e.g., advanced dementia patient who pulls out dialysis needles) or because the patient's condition is too unstable (e.g., profound hypotension).
- Those who have a terminal illness from non-renal causes (acknowledging that some in this condition may perceive benefit from and choose to undergo dialysis).
- Those with stage 5 CKD older than age 75 years who meet two or more of the following statistically significant very poor prognosis criteria (see **Recommendations No. 2 and 3**): 1) clinicians' response of "No, I would not be surprised" to the surprise question; 2) high comorbidity score; 3) significantly impaired functional status (e.g., Karnofsky Performance Status score less than 40); and 4) severe chronic malnutrition (i.e., serum albumin less than 2.5 g/dL using the bromocresol green method).

## Resolving Conflicts about What Dialysis Decisions to Make

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### Recommendation No. 7

**Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis.**

If a time-limited trial of dialysis is conducted, the nephrologist, the patient, the patient's legal agent, and the patient's family (with the patient's permission to participate in decision-making) should agree in advance on the length of the trial and parameters to be assessed during and at the completion of the time-limited trial to determine whether dialysis has benefited the patient and whether dialysis should be continued.

### Recommendation No. 8

**Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made with regard to dialysis.**

Conflicts may occur between the patient/legal agent and the renal care team about whether dialysis will benefit the patient. Conflicts also may occur within the renal care team or between the renal care team and other health care providers. In sitting down and talking with the patient/legal agent, the nephrologist should try to understand their views, provide data to support his/her recommendation, and correct misunderstandings. In the process of shared decision-making, the following potential sources of conflict have been recognized: 1) miscommunication or misunderstanding about prognosis; 2) intrapersonal or interpersonal issues; or 3) special values. If dialysis is indicated emergently, it should be provided while pursuing conflict resolution, provided the patient or legal agent requests it.

## Providing Effective Palliative Care

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### Recommendation No. 9

**To improve patient-centered outcomes, offer palliative care services and interventions to all AKI, CKD, and ESRD patients who suffer from burdens of their disease.**

Palliative care services are appropriate for people who chose to undergo or remain on dialysis and for those who choose not to start or to discontinue dialysis. With the patient's consent, a multi-professional team with expertise in renal palliative care, including nephrology professionals, family or community-based professionals, and specialist hospice or palliative care providers, should be involved in managing the physical, psychological, social, and spiritual aspects of treatment for these patients, including end-of-life care. Physical and psychological symptoms should be routinely and regularly assessed and actively managed. The professionals providing treatment should be trained in assessing and managing symptoms and in advanced communication skills. Patients should be offered the option of dying where they prefer, including at home with hospice care, provided there is sufficient and appropriate support to enable this option. Support also should be offered to patients' families, including bereavement support where appropriate. Dialysis patients for whom the goals of care are primarily comfort should have quality measures distinct from patients for whom the goals are aggressive therapy with optimization of functional capacity.

### Recommendation No. 10

**Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care.**

Good communication improves patients' adjustment to illness, increases adherence to treatment, and results in higher patient and family satisfaction with care. Patients appreciate sensitive delivery of information about their prognosis and the ability to balance reality while maintaining hope. In communicating with patients, the critical task for clinicians is to integrate complicated biomedical facts and conditions with emotional, social, and spiritual realities that are equally complex but not well described in the language of medicine. This information must be communicated in a way that patients, legal agents, and families can understand and use to reach informed decisions about dialysis and transplantation options. Patients' decisions should be based on an accurate understanding of their condition and the pros and cons of treatment options. To facilitate effective communication, reliance upon a multidisciplinary approach including nephrologists, intensivists, and others as appropriate is warranted. Decisions about acute renal replacement therapy in AKI should be made in the context of other life-sustaining treatments. Intensive care physicians should be included in shared decision-making for kidney patients in the ICU to facilitate discussions on global disease or injury prognosis. Fellowship programs should incorporate training to help nephrologists develop effective, empathetic communication skills, which are essential in caring for this patient population.

# Recommendation Summary

## Pediatric Patients

### Establishing Family-centered Shared Decision-Making

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#### Recommendation No. 1

**Develop a patient-physician relationship that promotes family-centered shared decision-making for all pediatric patients with AKI, CKD, and ESRD.**

In addition to involving pediatric patients to the extent that their decision-making capacity allows, the nephrologist should involve parents in determining health care decisions. If the parents request to involve other family members in shared decision-making, this request should be honored. If the treating nephrologist believes that a pediatric patient's parents are making decisions inconsistent with the best interest of their child, the nephrologist should involve medical ethics consultants or hospital ethics committees, mental health professionals, pediatricians specializing in child abuse and neglect, mediators, or conflict resolution specialists. These experts can assist in determining the reason for the parents' treatment choice and in determining an appropriate course of action. It is imperative that the nephrologist take steps to ensure that the pediatric patient has an adult advocate who is capable of participating in health care decision-making. Court involvement to order medical interventions over parental objections should be a last resort.

Family-centered shared decision-making process is recommended for all advance care planning discussions in which treatment options are discussed and treatment decisions are made. Education geared to the cognitive abilities of the parent and pediatric patient about the medical condition, prognosis, and available treatment options is an important component of the family-centered shared decision-making process. The pediatric patient's primary care physician, and in the case of the critically ill pediatric patient, their intensivist should be encouraged to participate in coordinating care related to treatment decisions made by the pediatric patient and his/her family. In the intensive care setting, patients with AKI will usually have multiple medical problems and the concept of shared decision-making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate, and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments.

### Informing Patients and Parents

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#### Recommendation No. 2

**Fully inform patients with AKI, stage 4 or stage 5 CKD, or ESRD and their parents about the diagnosis, prognosis, and all appropriate treatment options. Inform children and adolescents in a developmentally appropriate manner, and if feasible, seek their assent about treatment decisions.**

Treatment options include: 1) initiating or continuing dialysis; 2) transplantation for ESRD; 3) not starting dialysis and continuing optimal medical management; and 4) stopping dialysis and continuing to receive palliative treatment. The nephrologist and the medical team should make every effort to inform parents about the potential benefits and burdens of dialysis initiation

# Recommendation Summary

or dialysis withdrawal before providing or withdrawing treatment. In the rare circumstances when this is not possible, parents should be informed as soon as possible about the rationale for emergent initiation or withdrawal of dialysis and the efforts that were made to contact the parents before changing the medical plan. As a component of informed permission/informed assent, and in keeping with the on-going process of both shared decision-making and advance care planning, the treating nephrologist may determine that dialysis is no longer providing net benefit (i.e., the risks or burdens outweigh the benefits, the underlying condition is progressive and dialysis is only prolonging the dying process without improving the quality of life during the dying process). In this case, the nephrologist and the medical team should approach the family and discuss the undue burden of dialysis given the patient's medical condition and recommend stopping dialysis and intensifying palliative treatment. This will typically occur in the intensive care setting and intensivists should coordinate the shared decision making in the context of other aspects of supportive care. Children and adolescents should be given the opportunity to communicate their feelings and perceptions regarding the benefits and burdens of dialysis to the extent they desire to do so and their developmental abilities and health status permits. When seeking informed permission/informed assent for discontinuing dialysis, the medical team should explicitly describe comfort measures and other components of palliative treatment that will be offered.

## **Recommendation No. 3**

**Facilitate informed decisions about dialysis for pediatric patients with AKI, CKD or ESRD, discuss prognosis, potential complications, and quality of life with the patient, parents, and/or legal guardian.**

Nephrologists should rely on population-based survival data, using adjustments for confounders, to discuss prognosis, potential complications, and quality of life with patients, parents, and/or legal guardians. During these discussions, the nephrologist should acknowledge that the ability to predict survival in the individual patient is difficult and should reassure the patient and family that there will be ongoing opportunities for additional discussions regarding prognosis over time. Given the likelihood that health status changes for the better or worse are likely to occur in pediatric patients with AKI, CKD, and ESRD, discussions about survival odds and physical and psychosocial outcomes should be repeated when dramatic changes in health status occur. Each discussion regarding prognostic outcomes and patient/parent decisions regarding treatment should be documented in detail and dated. This documentation should be easily identified and accessible in the medical record. In the event of questionable understanding of the prognostic data, it is recommended that additional resources be offered to the pediatric patient and his or her family to ensure a reasonable understanding of likely outcomes and to allow for informed decision-making regarding treatment (see Recommendation No. 8).

## **Resolving Conflicts about What Dialysis Decisions to Make**

### **Recommendation No. 4**

**Establish a systematic due process approach for conflict resolution if disagreements occur about dialysis decisions. Use conflict resolution interventions when family members disagree with one another, when children disagree with their parents, when families disagree with the health**

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## **care team, or when the health care team disagrees about initiating, not initiating, or withdrawing dialysis.**

The following types of interventions are recommended to resolve conflicts: additional medical consultation(s); involvement of pastoral care; palliative care consultation; a multidisciplinary conference including sources of support for the patient/family from within or outside the institution; short-term counseling or psychiatric consultation for the child and/or family and/or consultation with a hospital-based ethics committee. When the health care team believes that non-initiation of dialysis would constitute medical neglect, consultation with available child protection specialists would be appropriate to help determine next steps. Court involvement should be used as an intervention of last resort.

## **Facilitating Advance Care Planning**

### **Recommendation No. 5**

#### **Institute family-centered advance care planning for children and adolescents with AKI, CKD, and ESRD. The plan should establish treatment goals based on a child's medical condition and prognosis.**

Family-centered advance care planning is recommended for infants with poorly functioning or nonfunctioning kidneys due to genetic conditions and those with a non-reversible urological or kidney abnormality. In the event that the health care team has information that the viability of a fetus with suspected multisystem organ involvement is questionable, family-centered advance care planning should occur before the birth of the baby. This will allow the health care team to be able to act decisively in light of the neonate's health status and prognosis at the time of delivery.

Advance care planning should be an ongoing process in which treatment goals are determined and revised based on observed benefits and burdens of dialysis and the values of the pediatric patient and the family. The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be *strongly* encouraged to talk to their parents to ensure that they know the patient's wishes and agrees to make decisions according to these wishes. Ongoing discussions that include reestablishing goals of care based on the child's response to medical treatment and optimal quality of life is the mechanism by which advance care planning occurs. Discussions should include the pros and cons of dialysis as well as potential morbidity associated with dialysis. Kidney transplantation should be discussed if appropriate.

Children and adolescents should be allowed to participate in advance care planning commensurate with their preference and developmental status. Parent or pediatric patient questions regarding discontinuation of dialysis if the patient's medical condition becomes irreversible and non-responsive to currently available treatments should be addressed frankly. Such questions can be used as a springboard for obtaining information about parent and child wishes regarding end-of-life care. Assurance should be given that the pediatric patient's comfort is paramount in the event that dialysis is discontinued. In addition, such questions should be used as an opportunity to explicitly describe comfort measures and other components of palliative care.

## Making a Decision to Not Initiate or to Discontinue Dialysis

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### Recommendation No. 6

**Forgo dialysis if initiating or continuing dialysis is deemed to be harmful, of no benefit, or merely prolongs a child's dying process. The decision to forgo dialysis must be made in consultation with the child's parents. Give children and adolescents the opportunity to participate in the decision to forgo dialysis to the extent that their developmental abilities and health status allow.**

An example of a clinical situation in which forgoing dialysis is often considered is an infant with multisystem organ failure for whom dialysis would be burdensome and would serve only to prolong dying. Forgoing dialysis should also be considered for a pediatric patient whose kidney failure is a consequence of a primary health condition that is non-reversible, non-treatable, and terminal and for whom dialysis would cause undue suffering. Infants or children who would otherwise be expected to survive for years with conditions causing severe neurologic impairment and who develop ESRD should ordinarily not undergo dialysis or transplant. Examples might be an infant with anencephaly or severe pencephaly, or a child with a severe progressive demyelinating condition. In children with severe developmental disabilities, clinicians will need to discuss with parents the balance of the benefits to burdens of prolonging life with dialysis. An intensification of palliative care treatment should occur in conjunction with any decision to forgo dialysis.

### Recommendation No. 7

**Consider forgoing dialysis in a patient with a terminal illness whose long-term prognosis is poor if the patient and the family are in agreement with the physician that dialysis would not be of benefit or the burdens would outweigh the benefit.**

In pediatric patients who experience major complications from dialysis that may substantially reduce survival or quality of life, it is appropriate to discuss and/or reassess treatment goals, including considering forgoing dialysis or withdrawing dialysis and initiating or increasing the emphasis on goals commensurate with palliative care. Alternatively, it is reasonable to initiate dialysis for patients with AKI or ESRD who have chronic illness from a non-kidney cause in whom outcome studies have been favorable. For example in HIV-associated nephropathy, dialysis has the potential to improve the quality of life in children.

### Recommendation No. 8

**Consider the use of a time-limited trial of dialysis in neonates, infants, children, and adolescents with AKI or ESRD to allow for the assessment of extent of recovery from an underlying disorder.**

In an intensive care setting, neonates, infants, children and adolescents with AKI or ESRD as a result of an underlying disorder may be candidates for initiating time-limited trials of dialysis. The purpose of such a trial would be to establish the extent of recovery from the underlying disorder and/or to determine the balance of benefits to burdens that continued life enabled by dialysis provides to the child. The initiation of dialysis in conjunction with extra-corporeal

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membrane oxygenation (ECMO) is an example of a time-limited trial. It is considered time-limited in that the dialysis is most often discontinued when ECMO is withdrawn due to patient non-viability.

## Providing Effective Palliative Care

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### Recommendation No. 9

**Develop a palliative care plan for all pediatric patients with ESRD from the time of diagnosis and for children with AKI who forgo dialysis. The development of a palliative care plan is a continuation of the process of advance care planning and should be family-centered.**

The terminally ill child, family and child's physician(s) should be involved in developing and executing a palliative care plan, based on their preferences concerning goals of care and decisions regarding testing, monitoring, and treatment. With the patient and family's permission, health care professionals with expertise in hospice and palliative medicine should be involved in co-managing the medical, psychosocial, and spiritual aspects of end-of-life care for the child and family. The nephrology team along with the child's pediatrician and other medical providers should offer bereavement support to the patient's family. In the case of a long-standing relationship with the pediatric patient, nephrology team members are encouraged to send a condolence card to the patient's family. Nephrology team members should be given complete autonomy regarding attendance at a pediatric patient's funeral or memorial service. Nephrologists and the child's health care team are strongly encouraged to seek support, in dealing with the child's dying process and death in the event that that the situation causes significant stress that interferes with baseline functioning at work or home.