

## **Recommendations for Addressing End-of-Life Care in ESRD**

Excellence in renal palliative care requires expertise in clinical management of problems in multiple areas. Listed below are eight areas that each dialysis facility should consider in offering palliative care to their patients:

- ❑ Structure and process of care
- ❑ Physical aspects of care
- ❑ Psychological aspects of care
- ❑ Social aspects of care
- ❑ Spiritual aspects of care
- ❑ Cultural aspects of care
- ❑ Care of imminently dying
- ❑ Ethical and legal aspects of care

The guideline below serves to provide each dialysis unit with recommendations for palliative care. It is hoped that from this list, dialysis unit staff may be able to implement part or all of these recommendations to provide excellent care to the ESRD patient.

### **Structure and Processes of Care**

- ❑ Create plan of care with interdisciplinary team, patient and family
  - Identify patients that need end-of-life care planning by asking “would I be surprised if this patient died in the next year?” at least monthly or after a change in the patient’s condition
  - Assessment for these patients should include:
    - Documentation of decision-making capacity
    - Diseases status, including diagnoses and prognosis
    - Comorbid medical and psychiatric disorders
    - Physical and psychological symptoms
    - Functional status
    - Nutritional status
    - Social, cultural, and spiritual concerns
    - Advance care planning concerns and preferences, including appropriateness of referral to hospice
  - Cognitive capacity should be assessed at initiation of dialysis and yearly
- ❑ Plan of care should reflect values, goals and needs of patient and family with professional support and guidance
  - Establish goals with patient and family and assess the changing benefit/burden
  - Achieve input from patient, family, caregivers and health care providers, palliative care specialist, caregivers, clergy, friends, and others
  - Make changes based on evolving needs and preferences
  - Share information, provide support and decision making, develop and carry out plan and communicate with all involved
  - Document treatment and care setting alternatives
  - Make treatment decisions based on goals of care

- Provide services to the patient from the interdisciplinary team consistent with the plan of care
  - Team should include nephrology professionals with education in palliative care and ability to meet physical, psychological, social, and spiritual needs of patient /family.
- Consider the use of appropriately trained volunteers
- Educate and train the interdisciplinary team in end-of-life issues
- Provide for quality improvement in clinical and management practices
  - Require regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of the care provided
  - Incorporate attention to the following:
    - Safety
    - Timeliness
    - Patient-centered care
    - Beneficial and/or effective care
    - Equity
    - Efficiency
  - Establish QI improvement policies and procedures
- Recognize the emotional impact on the care team of providing care to patients with ESRD and their families
  - Offer emotional support
  - Develop appropriate policies and procedures
- Develop relationship with one or more hospices and other community resources
  - Inform patients and families about hospice and other community based health care resources
- Consider the appropriateness of the physical environment when working with the patient and family

### **Physical Aspects of Care**

- Pain, symptoms, and side effects should be managed based on best evidence available
  - Consult with and/or refer to palliative care specialist
  - Regularly assess pain and non-pain symptoms
  - Reduce pain to a level acceptable to patient
  - Respond promptly to distress
  - Address barriers to pain management, including fears of side effects, addiction, hastening death
  - Implement risk management plan when using controlled substances
  - Educate patient and family of disease and consequences, symptoms, and side effects
  - Treat symptoms and side effects with pharmacological, non-pharmacological, and complementary/supportive therapies
  - Educate family about safe and appropriate comfort measures
  - Include a quality improvement process

### **Psychological and Psychiatric Aspects of Care**

- Assess and manage psychological and psychiatric issues systematically
  - Consult with and/or refer to specialist with training in psychological consequences and psychiatric co-morbidities

- Assess psychological reactions regularly
- Educate patient and family about disease, side effects and assess care giving needs, capacity and coping strategies
- Offer pharmacological, non-pharmacological and complementary therapies
- Communicate with children and cognitively impaired individuals in developmentally appropriate way
- Make a grief and bereavement program available to patients and families
  - Consult with and refer to professionals that specialize in grief, loss and bereavement
  - Offer bereavement services or work in conjunction with a hospice that does
  - Assess grief and bereavement routinely
  - Provide information to family on bereavement support services in community

### **Social Aspects of Care**

- Identify social needs of patients and families and develop care plan to respond effectively
  - Consult with and refer to specialized professionals
  - Assess the following:
    - Family structure and geographic location
    - Relationships
    - Lines of communication
    - Existing social and cultural networks
    - Perceived social support
    - Medical decision-making
    - Work and school settings
    - Finances
    - Sexuality/intimacy
    - Living arrangements
    - Caregiver availability
    - Transportation
    - Prescription, medicines and nutritional products
    - Needed equipment
    - Community resources
    - Legal issues
  - Hold routine patient and family meetings

### **Spiritual, religious, and existential aspects of care**

- Assess and respond to spiritual needs based on best available evidence and systematically apply
  - Consult with and refer to specialized professionals
  - Explore spiritual concerns on a regular basis and reevaluate
  - Support issues related to life completion in a manner consistent with patient and family cultural and religious values
  - Provide access to patient's clergy or pastoral care in their own traditions
  - Religious symbols should be sensitive to cultural and religious diversity

### **Cultural Aspects of Care**

- Assess and attempt to meet the culture specific needs of the patient and family

- Be respectful of their cultural preferences regarding disclosure, truth-telling and decision-making
- Cultural interpreter services should be available when needed

### **Care of the Imminently Dying Patient**

- Recognize signs and symptoms of impending death and communicate this phase to the patient and family
  - Revise care plan to meet needs of patient and family
  - Document patient and family wishes regarding care setting for death
  - Refer to hospice, or reintroduce hospice
  - Educate regarding signs and symptoms of approaching death

### **Ethical and Legal Aspects of Care**

- The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care
  - Consult with and refer to specialized professionals
  - Patients with decision-making capacity should decide what level of involvement he/she would like to have in making decisions
  - Surrogate should be identified for patients without decision-making capacity.
  - Promote advance care planning
- Be aware of and address ethical issues that arise in end of life care
  - Prevent or resolve ethical dilemmas by using ethical principles. Considerations include:
    - Beneficence
    - Respect for person and self-determination
    - Regulatory requirements for truth-telling
    - Capacity assessment
    - Confidentiality
    - Assent and permission for persons not of legal age
    - Informed consent
    - Attention to justice and nonmaleficence
    - Associated avoidance of conflicts of interest
  - Care should be consistent with professional code of ethics

Modified from: National Consensus Project for Quality Palliative Care

For more info: Mid-Atlantic Renal Coalition

1527 Huguenot Road  
 Midlothian, VA 23113  
 804-794-3757  
[marc@nw5.esrd.net](mailto:marc@nw5.esrd.net)