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## FAST FACTS AND CONCEPTS #163

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**Background** Care of chronic kidney disease (CKD) patients requires expertise in advance care planning (ACP), including attention to ethical, psychosocial, and spiritual issues related to starting, continuing, withholding, and stopping dialysis. This Fast Fact reviews key concepts of the ACP process for CKD patients. *Fast Facts* #207 and 208 discuss decision-making and management at the time of dialysis withdrawal.

### Barriers to ACP

- **Dialysis patients are not aware of their poor prognosis** and falsely assume they can be kept alive indefinitely on dialysis; end-of-life issues are commonly avoided until late in the illness.
- **Many health professionals believe that ACP may destroy hope** and that the focus of care should be on their "life-sustaining therapy," such as dialysis.
- **Cognitive dysfunction** associated with advanced CKD may prevent the ability for meaningful participation in ACP. Discussions must occur early in the illness while comprehension and decision-making capacity are preserved.

### Key aspects of ACP in CKD (See *Fast Fact* #162 for general ACP recommendations)

- **ACP should be initiated *prior* to the need for dialysis.** The importance of early discussions is underscored by the fact that only ~ 60% of nephrologists would consider stopping dialysis for a non-decisional patient with unclear prior wishes.
- **Include family in ACP discussions:**
  - **CKD patients are often afraid to talk to their loved ones** about their preferences; some patients will choose to prolong their time on dialysis due to family pressure.
  - **Surrogates must be aware of patient preferences** and the values upon which these preferences were based.
  - **Including family is critical in achieving many of the goals of ACP** such as strengthening relationships with and relieving emotional and financial burdens on loved ones.
- **Provide detailed information as part of pre-dialysis education:**
  - **All treatment options** should be fully reviewed: 1) available dialysis modalities, 2) not starting dialysis and continuing conservative management, 3) a time-limited trial of dialysis, and 4) stopping dialysis with expectation of death. (See below for clinical practice guidelines on not starting or discontinuing dialysis.)
  - **Estimate prognosis** (see *Fast Fact* #191). The annual death rate for patients initiating dialysis is 20-25%; 15-25% of these deaths result from decisions to withdraw dialysis. Patients with CKD who elect dialysis generally experience progressive functional decline over months to years, punctuated by episodes of life-threatening complications. Elderly or chronically ill patients with co-morbid diseases, at the initiation of dialysis, can be expected to have greater complications and a shorter survival. Poor prognostic factors such as older age, low serum albumin, poor functional status, and comorbid illnesses such as diabetes and cardiovascular disease can be used to estimate prognosis. Anuric patients, who elect to not initiate or discontinue dialysis, typically survive for 7-14 days. The prognosis is longer for patients with residual renal function who continue to make urine.
  - **Emphasize how you expect their illness and proposed treatments will impact their daily**

**function.** Discuss the impact of the various dialysis options on day-to-day function.

**Guidelines for not starting or withdrawing dialysis (1):**

1. Patients who, being fully informed and making voluntary choices, decline to begin or request dialysis be stopped.
2. Patients who no longer possess decision-making capacity, but who have previously indicated refusal of dialysis (oral or written).
3. Patients who do not possess decision-making capacity and whose surrogate declines dialysis or determines it should be discontinued.
4. Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.
5. Patients whose medical conditions precludes the technical process of dialysis.

**References**

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**ACGME Competencies:** Medical Knowledge, Patient Care, Systems Based Practice; Interpersonal and Communication Skills

**Keyword(s):** Communication, Psychosocial and Spiritual Experience: Patients, Families, and Clinicians

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