

## Frequently Asked Questions About End-of-Life Care for Renal Patients

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## **Answers to Frequently Asked Questions About End-of-Life Care for Renal Patients**

**1. How do major religions feel about people choosing to stop dialysis?**

Many organized religions, such as the Roman Catholic religion, the Eastern Orthodox religion, and most Protestant denominations believe it is acceptable for people to stop dialysis if the suffering involved with dialysis outweighs the benefits. Some religions, such as Orthodox Judaism and Islam, believe it would be acceptable to stop dialysis only if the patient is imminently dying. If patients have concerns about their religion's views on stopping dialysis, it is suggested that the patient consult with their clergy before making a decision to stop dialysis.

**2. How do we know that stopping dialysis is not suicide?**

Suicide occurs when a patient takes an action to cause his or her death. Examples of suicide are taking an overdose of medication or killing oneself with a gun. Patients who commit suicide do not die naturally. When a patient stops dialysis, the cause of death is kidney failure. The death is natural. Before a patient makes a decision to stop dialysis, he or she should be evaluated for depression and other treatable disorders. Discussions also should be held between the patient, the patient's family and loved ones, and members of the treating renal care team. Others, such as the patient's clergy, the primary care physician, etc., may also be involved in these discussions.

**3. Does choosing to stop dialysis mean that staff and family have let the patient down?**

The short answer to this question is "No." Patients usually choose to stop dialysis because they are no longer satisfied with their quality of life. When a patient asks about stopping dialysis, it is important for the renal care team to evaluate the patient to be sure that there are no treatable, reversible causes of the patient's dissatisfaction with dialysis. If after a full evaluation and therapeutic interventions as appropriate, the patient makes an informed decision to stop dialysis, the patient's wishes should be respected. Even after stopping dialysis, medical care should continue and patients' symptoms should be treated. No one has "let the patient down" if a decision has been made to stop dialysis.

**4. Does it mean that the family and staff want to get rid of the patient when a patient chooses to stop dialysis?**

The short answer again is "No." Dialysis staff are like most health care providers: they want to treat people to help them to live productive, happy lives free of pain and suffering. Usually when a patient asks to stop dialysis, extensive discussions are held between the patient, his or her loved ones, and members of the dialysis staff to understand why the patient is choosing to stop dialysis. As part of these discussions, the dialysis staff will strive to identify and treat any of the possible symptoms that are contributing to the patient's poor quality of life before simply stopping dialysis. Unfortunately, for some patients, the burdens of their illnesses and the need for dialysis at some point becomes overwhelming and causes more suffering than benefits. If this is the case and no treatments are likely to improve the patient's quality of life, the decision to stop dialysis may be made. In these cases, the dialysis staff is often saddened by the decision to stop dialysis but they remain supportive of the patient's decisions. Usually members of the dialysis staff will continue to visit with and care for patients who have stopped dialysis.

**5. Do life insurance companies pay survivors if people choose to stop dialysis?**

Yes. Stopping dialysis is a natural death so life insurance policies are paid.

**6. How long does it take to die if a patient stops dialysis?**

Most patients who stop dialysis die within 8 to 12 days. An occasional patient who has near normal urine output may live several weeks to a month. Patients who have other illnesses may die only a few days after stopping dialysis.

**7. Is it painful to die after stopping dialysis?**

Not usually. Patients who stop dialysis usually become very sleepy after a few days and then die in their sleep. Dying from stopping dialysis is considered to be one of the less painful ways to die. If a patient has pain, it can be treated with medications.

**8. How come some patients don't die within the predicted time period?**

Some patients who are very sick with infections, heart disease, or lung disease do not even live a week after stopping dialysis. Other patients who have some kidney function left may live several weeks to a month.

**9. Are there medications a patient can take to help in this period of time of no dialysis?**

Yes. Patients can take a medicines to relieve shortness of breath and pain. Patients can also take medicines to relieve muscle jerks that may occur. Patients who are short of breath can also use oxygen. Anti-nausea medications can be helpful too.

**10. Can patients finally eat whatever they like when they stop dialysis?**

Yes, patients may eat what they want. Some patients will continue to limit their fluid intake to avoid fluid building up in the lungs. These issues will be discussed with the patient who chooses to stop dialysis. Occasionally, some patients do not want to limit their fluid intake and make an agreement with the dialysis unit to have fluid removal without dialysis after they stop their dialysis treatments. This process is called ultrafiltration. Although some patients who stop dialysis want to have ultrafiltration if fluid builds up in the lungs before they die, ultrafiltration is rarely needed in dialysis patients who stop dialysis.

**11. Will the patient who stops dialysis swell up like a balloon?**

No, not if the patient is careful about liquid intake or receives ultrafiltration. Most patients who are dying are not thirsty and so drinking a lot of fluid after stopping dialysis rarely happens.

**12. Do you have to go to a hospice to get treated?**

Most hospices actually provide care in your home. Less than 5% of hospices are in hospitals.. The Medicare hospice benefit does allow for patients who are treated at home to go to the hospital to manage pain or other symptoms that cannot be managed well at home.. The Medicare hospice benefit also provides respite care so that caregivers can get rest. This benefit allows patients to get care in a residential facility, nursing home, or a hospital for up to 5 days.

**13. Can hospice help families with patients who stop dialysis?**

Yes, hospice physicians, nurses, therapists, and social workers are familiar with helping patients and families who have only a short time to live.

**14. Are there any special circumstances that hospice needs to be aware of when they receive a referral for a renal patient?**

Yes, hospices will need to know the patient's expected survival after stopping dialysis.

**15. What if my doctor does not want to refer me to hospice?**

It is important to find out why. Some doctors are not familiar with hospice and might prefer not to become involved. It is important to have a frank discussion with the doctor regarding quality of life and life expectancy. If the doctor does not want to have this discussion or is uncomfortable with hospice, it might be helpful to talk with a doctor who works with hospice patients. If needed, care can be transferred to another doctor who is comfortable with hospice.

**16. If the patient feels a whole lot better once he stops dialysis, does this mean that he is getting better and that he should go back on dialysis?**

No. Patients who stop dialysis often report feeling better for the first 3 to 4 days after stopping dialysis. Patients often say that just having made the decision takes a burden off their minds, and they feel more relaxed. Also because patients are not going to dialysis treatments 3 times a week, they are less tired from the travel back and forth and do not have the "washed out" feeling that many patients get after dialysis.

**17. Because Medicare stops paying the renal team once a patient goes with hospice and stops dialysis does this mean that the team can longer be contacted?**

Most renal care teams want to be involved in the patient's care after the patient stops dialysis. They are happy to answer questions the patient or family may have and to prescribe medications as needed to be sure that the patient is comfortable.

**18. Is it always true that a patient must stop dialysis in order to get hospice?**

No. Patients who are dying from some other condition such as cancer or heart disease may continue dialysis while receiving hospice care.

**19. Do younger patients have the right to stop dialysis?**

Yes. Regardless of age, the reason why dialysis is stopped is because the burdens associated with it are too great. Occasionally even infants and children have dialysis stopped because continued life with dialysis is causing extreme suffering without a likelihood of benefit.

**20. If an older person has dementia, is it homicide for the family to stop dialysis?**

No. Patients with dementia often do not understand the dialysis process. Sometimes it is even necessary to restrain them (literally tie them down) to keep them from pulling out their dialysis needles during the treatment. Undergoing dialysis can cause severe agitation for patients with dementia. Patients with advanced dementia who do not understand the dialysis treatment and cannot cooperate with it are patients for whom stopping dialysis should be considered. Death from stopping dialysis is due to kidney failure, not homicide. What families (and staff) perceive regarding how a patient is tolerating dialysis, especially in the demented state, is an important consideration when weighing the patient's quality of life.

**21. What does the renal care team recommend for the patient who is thinking about stopping dialysis?**

Various organizations such as the National Kidney Foundation, the Renal Physicians Association, and the American Society of Nephrology have published guidelines on how to evaluate the patient who is thinking about stopping dialysis. Patients should be evaluated according to these guidelines before a decision is made. Patients and families can request such an evaluation by the renal care team prior to any decisions being made.

**22. Can a patient not tell his family that he is stopping dialysis?**

Patients are legally allowed not to tell their family that they are stopping dialysis. However, not telling the family is usually a very, very, very bad idea. Families are unprepared for the patient's decision, and the unpreparedness causes them severe emotional suffering. Major decisions such as stopping dialysis are best made with the patient's family. Telling the family and discussing it with patient and family (even if it takes a little longer) is likely to facilitate reconciliation and peace with the decision and is usually well worth the time and effort.

**23. Can a patient who is stopping dialysis donate any body parts?**

Patients who are stopping dialysis are not able to donate internal organs such as hearts, lungs, or livers, but they may be able to donate tissues. It is best for a dialysis patient who is stopping dialysis to express their wishes in advance so arrangements could be made at the time of death for an evaluation of the patient for tissue donation.

**24. Will the police come to a patient's home if he stops dialysis and dies? Should they be notified ahead of time?**

No, it is not necessary to call the police. It is best for the patient to be taken care of by hospice after the patient stops dialysis. When the patient dies, the hospice should be called, and a hospice nurse will come to the home and assist the family in making necessary arrangements.

**25. Can a person stop dialysis and die in the hospital?**

In past years, most patients who stopped dialysis died in the hospital. In recent years, there have been changes in insurance coverage. Insurance companies may deny hospitalization coverage for a patient who has stopped dialysis. Hospices can help dialysis patients who have stopped dialysis to die comfortably at home.

**26. Will all insurances pay for hospice?**

Many, if not most, will pay for in-patient hospice. Patients and families should discuss this matter with the dialysis social worker prior to making the decision to stop dialysis to be sure what type of coverage the patient has with regard hospice.

**27. Would it be okay for little children to visit a patient who has stopped dialysis?**

In most cases, it is encouraged to have little children visit beloved family members who have stopped dialysis. The dialysis patient then has an opportunity to say goodbye to the child. The child is also given the opportunity have a final memory of the patient.