

# What happens if someone stops dialysis?

For many people with kidney failure, dialysis or a kidney transplant enables them to live longer and enjoy their quality of life. However, this may not be the case for everyone and each person has the right to choose how — or even if — they want to receive treatment for chronic kidney disease. Without life-sustaining dialysis or a kidney transplant, once a person with kidney disease reaches Stage 5 (end stage renal disease (ESRD)), toxins build up in the body and death usually comes within a few weeks.

The decision to stop treatment should be an informed and voluntary choice. Experts recommend that patients talk with their physicians and perhaps a social worker or therapist to fully understand their choices and know what to expect. It's important to rule out depression or other issues that may affect how the patient feels about life-sustaining treatment. Ideally, the physician-patient relationship encourages shared decision-making. With shared decision-making, the doctor fully informs the patient about treatment options, including stopping (or not starting) dialysis and planning for end-of-life care.

With advance planning, patients who have made the decision to stop treatment can spend their last days how and where they choose — with loved ones or alone at home, in hospice or in the hospital. The patient can also get help with how to tell loved ones about their decision.

## Talking to family members about stopping dialysis

Frequently, visitors to the DaVita.com discussion forum who have a family member that wishes to stop treatment will ask, "What will happen once dialysis is stopped?" It is natural for loved ones to be concerned, because without lifesaving treatment death will occur, usually within a few weeks. However, it is the patient's right to make this decision and sometimes, knowing that death can be pain-free and peaceful for the person with end stage renal disease (ESRD), helps ease family members' fears.

There are many reasons why someone with ESRD may not want to continue or start dialysis. Some people feel they've lived a full life and don't want to bother with additional surgery and treatments. For dialysis, a person will need an access placement and hemodialysis three times a week, or peritoneal dialysis every day. Some people who are already on dialysis may feel that the treatment is no longer maintaining or improving their health because they are unable to live independently or enjoy a certain quality of life.

Studies have shown that people most likely to withdraw from dialysis are older and living in nursing homes. They often have health problems in addition to kidney disease, and suffer more severe pain. They usually have physical limitations that restrict normal daily activities.

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If a loved one decides to stop dialysis, it's important that family members try to understand and respect that decision. The patient's treatment team should be available to make sure the patient and family members understand the effects of the decision.

## Preparing for stopping dialysis — Advance Directives and Hospice

While talking about death and dying can be difficult, most families find it is a relief to have a plan in place for when the time does come. Planning for care and respecting the wishes of the patient make end-of-life decisions easier. An Advance Directive can help family members know what the patient wants regarding end-of-life care so the family doesn't have to make those decisions for the patient. An Advance Directive is a legal document that spells out a person's wishes regarding future crisis care. All adults should have an Advanced Directive. Having an Advance Directive lets everyone know what to do if you become unable to communicate those wishes.

There are two basic kinds of Advance Directives: living wills and health care proxies (durable power of attorney for health care decisions). You'll want to make sure everyone involved with your care has a copy of your Advance Directive. State laws determine how people can direct their care. An attorney can determine the legally appropriate form for your state. If you have questions about an Advance Directive, please talk with your physician or an attorney.

Patients who stop dialysis receive what's called palliative care. Palliative care, also called comfort care, focuses on helping patients stay as comfortable as possible during the time remaining. When someone has made the decision to stop dialysis, hospice can be referred by their physician. Hospice, a form of palliative care, provides pain relief and symptom control and can take place in the patient's home, at a hospice facility or in the hospital. Hospice is a service that can be of help to end stage renal disease patients and their family members; however, it is used by less than half of those who withdraw from dialysis. For more information on hospice, talk to your physician.

## What to expect once dialysis is stopped

Without dialysis, toxins build up in the blood, causing a condition called uremia. The patient will receive whatever medicines are necessary to manage symptoms of uremia and other medical conditions. Depending on how quickly the toxins build up, death usually follows anywhere from a few days to several weeks.

As the toxins build up, a person may experience certain physical and emotional changes. The body has a normal, natural way to prepare itself to stop. Understanding what's happening can help the patient's friends and family members prepare to help their loved one. In the final days, the body starts to shut down. In most instances, the shut-down is an orderly series of physical changes which may include:

- Loss of appetite and fluid overload
- Sleeping most of the day
- Restlessness

- Visions of people who don't exist
- Disorientation, confusion and failure to recognize familiar faces
- Changes in breathing (Normal breathing patterns may become shallow, irregular, fast or extremely slow. There may be periods of breathing that sound like panting. Exhaling may create a moan-like sound. This is not distress, but the sound of air passing over the vocal cords. Changed breathing patterns indicate decreased circulation in the internal organs and buildup of waste products. Elevating the head and/or turning onto the side may increase comfort.)
- Congestion (If saliva and mucus collect in the back of the throat, you may hear a gurgling sound. While the sound can be distressing to hear, it's a normal response to a fluid imbalance and the inability to cough up normal secretions. It may help to raise the head. Turning the head to the side allows gravity to drain the congestion.)
- Changes in color and skin temperature

Patients who choose to stop or not start dialysis are not required to eat or take in fluids. In most cases, a patient is allowed to eat or drink if they want to, but forcing fluids or nutrition is not recommended.

Medicines can be given for pain, anxiety, agitation or congestion. However, other medicines are often stopped when a person decides to quit dialysis treatments, since treating the chronic medical conditions is no longer a priority.

As the body's systems shut down, a person slips into unconsciousness and the heart stops beating.

Most people who pass away from kidney failure have what family members and caregivers describe as a "good death." A study reported that patients who discontinued dialysis described a good death as pain-free, peaceful and brief. The patients' families echoed this sentiment, adding a good death included having loved ones present at the end.

### **Treasure the time you have**

When the dialysis patient and their loved ones are prepared for the final days, the time remaining can be spent in companionship, reminiscing, laughing and crying. Many people never have the opportunity for closure, many kidney failure patients and their loved ones say they are grateful for the opportunity to express affection and say goodbye.

### External links

- Clinical practice guideline on shared decision-making in the appropriate initiation of and withdrawal from dialysis – National Guideline Clearinghouse
- Which patients choose to stop dialysis? – Oxford Journals Nephrology Dialysis Transportation
- Death by withdrawal from dialysis: a 20-year clinical experience – JAMA Journal of the American Society of Nephrology

## Related articles on DaVita.com

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