



NON-DIALYSIS SUPPORTIVE CARE





Non-dialysis supportive care

PEACE OF MIND

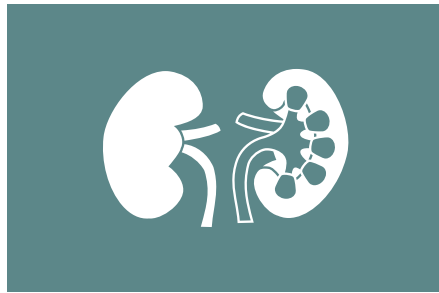
You have the right to make decisions about your own treatment, including the decision not to start or to stop dialysis. Death and dying are not easy things to talk about. Yet it's important to speak with your family, friends, and healthcare team about your treatment choice, so that you can plan for **end-of-life care** with peace of mind.

Non-dialysis supportive care is an active treatment choice in which kidney disease is treated with medication and diet, with no plans for a transplant or dialysis. In many communities it's called **conservative care**, *conservative treatment* or *conservative management*. However, people sometimes think that the term *conservative* implies that your care will be limited, which isn't the case, so we prefer the term *non-dialysis supportive care*.

If you choose non-dialysis supportive care, either because you decide not to start dialysis or because you've decided to stop, you will receive high quality medical care and, as your kidney function gets worse, your healthcare team will help you prepare for the end of life.

The goal of non-dialysis supportive care is to preserve kidney function for as long as possible through diet and medication, knowing that this can slow the decline in kidney function, but may not prevent it. You may continue to feel well for quite some time. It is a treatment choice that may not prolong life but will help to manage symptoms, both physical and emotional, so that you can live the way you want for your remaining time, without the disruption of dialysis treatments. The goal is to live the way you want, right up to the end of life.

Non-dialysis supportive care



Why do people choose non-dialysis supportive care?

Some people choose this type of care because they have other serious medical conditions, are not candidates for a transplant, are elderly, and/or feel the burden and discomfort of dialysis outweigh the potential benefits. This may include the difficulty in performing dialysis, symptoms and life disruption with dialysis, including travel time. They decide that non-dialysis supportive care is a reasonable choice for them because they will receive active, supportive physical and emotional care right up until the end of life. In short, it may offer them greater quality of life.

Depending on where you are in life and other reasons like your overall health, it is wise to consider several factors as you make your treatment decision. Sometimes it could be your doctor who raises the subject, especially if they feel that dialysis treatments will not provide any further benefit for you. But the final decision is yours and you can change it at any time.

Choosing not to start dialysis

Some people choose not to start dialysis. Dialysis requires surgery to provide access to the bloodstream (for hemodialysis) or a catheter inserted into your abdomen (for peritoneal dialysis). After surgery, there is often a recovery period before dialysis can be started. Then there are the treatments themselves, which take up time throughout the day or week, depending on the type of dialysis.

Dialysis is a treatment intended to improve life, not cause more harm or suffering. Sometimes people have other health complications which dialysis will not help. Others feel that the burden of dialysis treatments will not provide any real health benefit or give them the enjoyment of life they would like.

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If you choose non-dialysis supportive care

If you choose this type of care, you'll continue to have the full support of your healthcare team, including regular doctor visits and routine tests. You will continue to take medication for kidney disease and make healthy food choices, including some occasional food treats. You may still need to restrict the amount of fluid you drink to avoid breathing difficulties. Medication is always available to help manage any pain you may have. Machines like respirators will not be used. At some point toward the end of life, you will begin to receive palliative care.



Palliative care

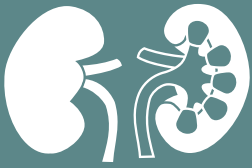
Palliative care (which is also called *end-of-life care* or *comfort care*) is the special physical, emotional and spiritual care that is given to people at the end of their life. The goal is to maintain the quality of living and ensure dignity in dying. It may include managing pain or discomfort, help with breathing and other supportive treatments.

Palliative care can be offered in hospital (sometimes in a special palliative care unit at the hospital), in a hospice, nursing home or at home. However, there may be limitations on the specific kinds of care that can be given in these different settings and not every type of care is possible at home.



NOTE

If you have an advance care plan, you might want to review it. If you don't have one, read **Chapter Six: Advance care planning**. It provides a more complete list of questions for you to think about.



Non-dialysis supportive care

NOTE

Choosing non-dialysis supportive care (which means no dialysis) is not considered suicide because the cause of death is kidney disease. Everyone has the right to decline or discontinue medical treatment. Insurance companies pay out insurance policies because the cause of death is kidney disease, not suicide.

Death from kidney disease is usually painless and peaceful. You might experience sleepiness and longer periods of sleep. You may or may not feel like eating or drinking. In all cases, you will receive help for whatever is troubling you. Your dignity is respected at all times.

Your healthcare team will introduce you to the palliative care resources available in your area when you need them.

Questions to ask yourself

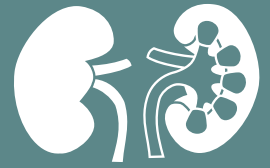
- Do I want to try in-centre hemodialysis knowing it will mean surgery, then travelling to a hospital or dialysis centre for hemodialysis treatments at least three times a week? Do I have someone to drive me and keep me company? Will this option allow me to do the things I want to in life?
- Am I willing to learn how to do peritoneal dialysis at home and do I have the energy to do it several times a day? Do I have someone who can help me, including managing my supplies?
- If I choose non-dialysis supportive care, what are the most important things I would like to do in the days, weeks or months remaining to me?
- Do I have people available to help me, no matter what I decide - family, friends, loved ones, professional support services?

Your feelings

It is very common to have a range of emotions when thinking about and deciding on treatment options and what they mean. You might feel anger, fear, sadness, confusion, anxiety or depression. Or you may have feelings of relief, acceptance and peace. You may experience any or all of the above. It can be good to talk about these feelings with your healthcare team because they can provide emotional support, practical suggestions, further information (which may ease your mind) and even medication or other treatments for anxiety or depression. Your healthcare team will also want to be sure that your decision is made voluntarily and that you aren't under any unusual stress or suffering from severe depression.

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Regardless of your treatment option, it is the quality of your life and your time that is important. If you have chosen no dialysis, this may give you the time to live and do the things you want to do with your loved ones until the end of life. It can be a time of peace with no surgeries and no machines. It can be a special time spent with family, loved ones and friends.

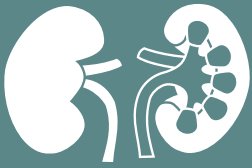


Talking with your family and loved ones

Although you are the ultimate decision-maker about what kinds of treatment you want or don't want, you may wish to consider how your family and loved ones will be affected by your decision. Talking with them about these matters can be difficult and painful, and sometimes, family members may not agree with your decision - they may be afraid, angry or unwilling to discuss it. You will want to help them understand the reasons for your decision. Many people like to involve their doctor, social worker or other healthcare team members in these discussions. They can answer questions, provide more details and discuss what resources are available to support you and your family.

Take your time - there is no need to rush the conversation. You can simply explain how you are feeling, what you would like to do with your time and why you feel that your decision is the best one for you.

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Where to go for more information

Your healthcare team is the best source of information about the kinds of support that are available in your region for non-dialysis supportive care, and later for palliative care. In particular, your social worker will have details about local resources.



Summary

- Non-dialysis supportive care is an active treatment choice in which kidney disease is treated with medication and diet, with no plans for a transplant or dialysis.
- You may choose not to start dialysis, or to stop dialysis treatments at any time.
- As the end of life approaches, you will receive palliative care, which is the special physical, emotional and spiritual care that is given to people at the end of their life.
- You and your family may find it difficult to deal with and talk about your feelings at this time; your healthcare team can support you throughout this process.