

Stopping Dialysis Treatment

What you need to know before deciding





Acknowledgements

We would like to thank all involved in the development of this document. This includes members of the working group, BC Renal committees, BC Centre for Palliative Care, patients and families, and key experts who provided feedback.

Purpose of this booklet

This booklet is designed to help patients and clinicians explore difficult conversations about stopping dialysis treatment. It is not intended for all patients on dialysis. It is, however, meant to act as a shared decision-making tool and designed to help health care providers and patients work together to make a decision that is best for the patient. The optimal decision takes into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values and preferences.

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Thinking about stopping dialysis

For many people whose kidneys have failed, dialysis is a muchappreciated life-saving treatment. However, the rigorous routine of dialysis can be physically and emotionally challenging. For some people these challenges can be so difficult that they would prefer to stop dialysis treatment altogether.

Stopping dialysis is a choice you can make if you feel your quality of life has declined to the point that you no longer want to continue with treatment. But before making such a life-altering decision, it's essential that you consider it very carefully. Your dialysis team can help you through this process by making sure you do not have underlying depression or other issues that could be changed to improve your quality of life. It is also important that you discuss your feelings about stopping dialysis with your loved ones. It is common to experience a range of emotions when thinking about ending dialysis. Some people feel sadness, confusion, anxiety or depression. Others have feelings of relief, acceptance, and peace. Death from kidney failure is usually painless and peaceful. It involves slipping into a coma (deep sleep) from which you will not wake up. If you are considering ending dialysis, you may experience any or all of these feelings.

Stopping dialysis treatment can offer you time to do the things you want to do before your end of life. It can be a time of peace, uninterrupted by medical procedures and machines, to be spent with family, friends and loved ones.



Related Document

BC Renal has created a document to assist you as you prepare for stopping dialysis treatment.

"Frequently Asked Questions about Stopping Dialysis: A guide for patients and families" helps answer the questions you may have about stopping dialysis treatment. Please visit the BC Renal website to view this document at:

BCRenalAgency.ca ► Health Professionals ► Clinical Resources ► Palliative Care



Share your thoughts with your loved ones

Many people find it difficult to talk to their family and friends about stopping dialysis. Still, it is best to discuss your thoughts and feelings openly. It will be easier if you are honest with your loved ones about how you feel, and acknowledge and accept each other's opinions and feelings.

Your doctor, nurse, social worker or spiritual advisor can provide guidance on how you might approach discussions about stopping dialysis with your family. It is often best to first speak with someone you trust and who makes you feel comfortable. If you wish, a family conference with your kidney doctor and social worker can be arranged to support you when you speak with your family.

There are also programs to assist your family and friends with grief during this difficult time. Speak with your health care team for more information about these resources.

Talk to your family doctor

After you have had the conversation with your loved ones, the next step is to talk to your family doctor. Talking to your doctor is important to help you plan and prepare for your end of life.

When booking your appointment, inform the office that you want to take time during your visit to discuss stopping dialysis. Your doctor will set aside more time for this important conversation.

A few points to consider and/or discuss with your family doctor:

- Will you talk openly and candidly with me and my family about my illness?
- What will my final days after dialysis be like?
- What decisions will my family and I have to make, and what recommendations can you give to help us with these decisions?
- What can you do to help me if I have pain or uncomfortable symptoms?
- Will you still be available to me when I am close to the end of my life?



Talk to your kidney doctor or nurse practitioner

Your kidney doctor or nurse practitioner will work closely with your family doctor to help you through the process of ending your dialysis treatment.

A few points to consider and/or discuss with your kidney doctor or nurse practitioner:

- After stopping dialysis, can I start again if I change my mind?
- Do I need to continue dialysis until all end of life arrangements have been made?
- After stopping dialysis, will my dialysis team stay involved in my care?
- Will stopping dialysis cause me pain or discomfort?
- Will my dialysis access stay in place?
- Will I be able to eat the food I want?

Talk with your community and rural team

If you live in a rural or remote community, difficulties with your dialysis treatment can bring up a range of issues. You may feel isolated or helpless. As your health declines, you may feel that moving to a kidney centre would be too much for you and your family. Stopping dialysis may seem like the only option. Before making any major decisions, discuss your thoughts and feelings with your health care team. Your team is there to help. A few points to consider and/or discuss with your community and rural team:

- What are my stay-at-home options as my health declines?
- Can I still dialyze at home?
- What services are available in my community?
- Will home care be available for me at my end of life?



Talk to spiritual care

Spiritual care is not only for those who are "religious." Anyone can benefit from non-judgmental spiritual care. As we reach the end of our lives it is common to look for meaning. It can be a great comfort to have someone who is trained to provide support at such times.

Some of us have cultural traditions that can provide support. The website <u>LivingMyCulture.ca</u> offers people from various backgrounds sharing their stories and wisdom about living with serious illness, end of life and feelings of grief.



What to expect when you stop dialysis

If you decide to stop dialysis, your dialysis team will work with your family doctor and a palliative care team, who are specialists in endof-life care. In addition to medical assistance, you and your family members may need emotional support. You may need medicine to help manage symptoms. Your palliative care team will discuss this with your family and kidney doctor.

As your condition declines, you may experience the following symptoms:

- Sleepiness and weakness
- Breathing changes
- Changes in body temperature
- Appetite changes
- Emotional changes
- Nausea
- Confusion (memory problems, disorientation)

If you experience any uncomfortable symptoms tell your health care team. There are many treatments for controlling these symptoms. You kidney care team may use assessment tools to manage your symptoms.

Your dialysis team can provide you a copy of the assessment tool. It can also be found by searching "Symptom Assessment" on the BC Renal website (<u>BCRenalAgency.ca</u>)

Related Document

BC Renal has developed symptom management materials to help you communicate how you are feeling and recommend common strategies to resolve symptoms. Visit:

BCRenalAgency.ca ► Health Info ► Managing my Care ► Symptom Assessment and Management

We are here to help you

Deciding to stop dialysis and confronting your end of life can be very difficult. It is a decision that must be discussed thoroughly with family and friends. This takes courage, and the decision must be yours. However, you are not alone. Your health care team will support you as you consider whether the decision to end dialysis is the right one for you.

Notes:	
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"This document expresses caring and assistance, and it has a reassuring tone which is helpful to me as I think about my options."



"This document has helped me think about my future. Even though I am not there yet, I am glad I have this information" ~Dolly

"I've always been a planner. When things are planned well in advance, I feel much less anxious about the future. Since death is an expected outcome, it just makes sense to plan for it." ~Jan



Another brochure you may find useful:



To view and download, visit: BCRenalAgency.ca ► Health Info ► Managing My Care ► Palliative Care

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