

BCRenal

Provincial Health Services Authority



Frequently Asked Questions about Stopping Dialysis Treatment

A guide for patients and families



Acknowledgements

The project team would like to thank everyone involved in the Integrated Palliative Nephrology project who contributed to this provincial effort. This includes members of the working group, BC Renal committees, BC Centre for Palliative Care, patients and families, and key experts who reviewed the evidence and developed educational materials such as this booklet.

This document is dedicated to Jan Frazelle, a patient partner who was instrumental in its development. BC Renal will be forever grateful for her commitment to helping fellow kidney patients feel empowered to make decisions in their kidney care.

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.

Dear Patient/Family Member,

This booklet was written to answer the questions that are most commonly asked about stopping dialysis treatment. The information may or may not apply to you. We understand this can be a challenging topic and further reflection and discussions are often needed with your dialysis care team, family, and care partners. The guide was written to be honest and straightforward. This may provoke feelings that are upsetting to you. We encourage you to read this guide with a loved one or a trusted friend.

You are not alone on this journey. Your dialysis team is here to help with your health care decisions. If you have questions or would like to speak to someone about what you have read in this document, please call your team at:

Dialysis Team Member _____

Phone Number _____

Yours sincerely,

Your dialysis team

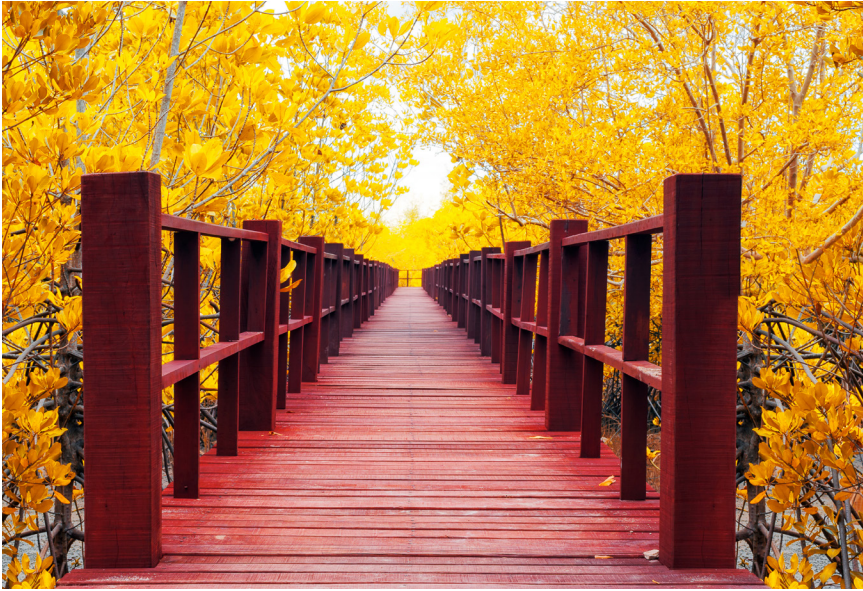


Related Document

For more information on having conversations about stopping dialysis treatment, please refer to “Stopping Dialysis Treatment: What you need to know before deciding”. Visit:

[BCRenalAgency.ca](#) ▶ [Health Professionals](#) ▶ [Clinical Resources](#) ▶ [Palliative Care](#)





I feel like stopping my dialysis treatment. Is this normal?

It's normal to feel obligated to continue with treatment. However, the rigorous routine of dialysis can be physically and emotionally challenging. 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 dialysis. 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 it isn't depression or other issues that could be changed to improve your quality of life.

If I stop dialysis, what happens next?

If you have decided that you would like to stop dialysis treatments, your dialysis team will work with your family doctor and palliative care team to set up a plan for your care. You or your family members may need emotional support. You may need additional medicines to help manage symptoms. The palliative care team will discuss this with your family and kidney doctor. Making arrangements for the palliative care team to ensure your end-of-life wishes are met can take from one to two weeks.

How long can I live after stopping dialysis?

Most patients who stop dialysis die within a week or two. Occasionally patients who have 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. In the end, you become drowsy and will slip into a coma. It is usually peaceful and free of suffering when effective supportive care is in place.

However, if you are experiencing heavy symptom burden that is causing physical or psychological suffering; there are other options available. Please refer to page 19 to learn more about Medical Assistance in Dying (MAiD).



What symptoms might I expect when I stop dialysis treatment?

When you stop dialysis and as your condition declines you may experience one or more of 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, we encourage you to discuss them with your health care team. There are many effective treatments for controlling these symptoms.

When I stop dialysis will I experience pain?

Death from kidney failure is usually painless and peaceful. It involves slipping into a coma (deep sleep) from which you will not wake up. Some people may experience pain from other illnesses they may have, or as a result of complications from long-term kidney failure.

Will I get very 'puffy' from the fluid build-up?

If you are careful about the liquids you drink, you should experience less fluid build-up. Most patients who choose to stop dialysis treatment are not thirsty so drinking a lot of fluid after stopping dialysis rarely happens.

Will I maintain mental alertness and my ability to think/speak clearly?

You may experience confusion, otherwise known as delirium. This is more likely to develop if you require high doses of opioid (pain) medications (e.g., hydromorphone or fentanyl) to control pain. There are very effective medications your doctor and health care team can use to help reduce distress related to confusion.

Is stopping dialysis committing suicide?

Stopping dialysis is not committing suicide. Dialysis is a life-supporting treatment; without it, natural death occurs due to organ failure. You always have the right to decide not to accept this treatment. You may wish to discuss this further with your religious or spiritual advisor. All hospitals have religious advisors, and your team can contact them for you.



Do younger patients have the right to stop dialysis?

Yes. Regardless of age, the decision to stop dialysis is a personal one. You have the right to discontinue at any time. Before making such a decision, however, you should speak to your kidney doctor (nephrologist) about any difficulties you experience with dialysis. There may be medication to help.

Can I change my mind and start dialysis again?

Yes, you can change your mind at any time. Your health care team wants what is best for you and will support any decision you make, including the decision to change your mind.



Preparing to Stop Dialysis

You may not be ready to stop dialysis treatment at this moment, however there may come a time when this may change. If your symptoms get worse it may be hard for you to think clearly, plan your future, and make your wishes known. It's best to plan for the future while your health is stable, not during a crisis.

What is Advance Care Planning?

Advance care planning begins by thinking about your beliefs, values, and wishes regarding future health care treatment. It is about having conversations with your close family, friends and health care providers so that they know the health care treatment you would agree to, or refuse if you become unable to express your own decisions.

Advance care planning also includes choosing a substitute decision maker. This is someone you trust to make healthcare

decisions on your behalf if you become unable. Tell family members where you keep your original documents.

Advance Care Planning documents may include:

- Power of Attorney
- Will
- Health Care wishes
- Substitute decision-makers
- End-of-life preferences
- Funeral arrangements
- Organ donation wishes

What is a “palliative approach” to care?

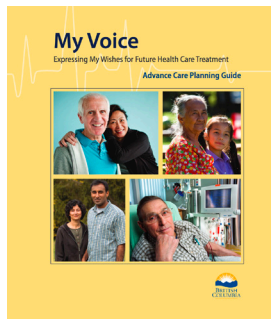
At any time during your dialysis treatment, you can get help to relieve your symptoms and improve your quality of life. This is called a palliative approach to care, and it is often important while going through dialysis treatment. If you decide that you want to stop dialysis treatment, then it’s time to focus even more on palliative care; sometimes referred to as “supportive care.”

Palliative care helps reduce pain and other symptoms. It helps you and your loved ones get the most out of the time you have left together, by focussing on what is most important to you.

i

Advance Care Planning

Learn about the options available to you in British Columbia outlined in the **My Voice: Expressing My Wishes for Future Health Care** guide. This guide is available at: <http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>



You may also visit the NIDUS website which is a personal planning resource centre at: www.nidus.ca

Your kidney social worker may also be able to provide you with a copy of the guide.



Related Document

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

BCRenalAgency.ca ► [Health Info](#) ► [Managing my Care](#) ► [Symptom Assessment and Management](#)

What are palliative care services?

Palliative care services provide physical, emotional, and spiritual support. You can get help to relieve pain, fatigue, anxiety, shortness of breath, nausea, and depression. Sometimes your doctor will provide you with palliative support. As well, you may need a specialized palliative care team who will work with you, and your doctor, to provide any additional care and services you need. Ask your kidney doctor or palliative care team if this is an option for you. Palliative care services may be available in your home, in a hospice facility, or at a hospital.

The type of services may vary by community and can include:

- Doctor and nursing care
- Pain management
- Medical equipment
- Medicines to ease symptoms
- Grief counseling for family and friends
- Social worker services
- Respite care, to give your caregivers a break



Kidney Services

Find out what services are available in your Health Authority at:

BCRenalAgency.ca ► [Health Info](#) ► [Palliative Care](#) ►
[Local ACP and Palliative Care Resources](#)

Once I decide to stop dialysis, how am I referred for palliative care services?

Ask your doctor about a referral to palliative services in your area. Your doctor will want to register you for palliative care benefits. BC Palliative Care Benefits cover the cost of home care support and certain drugs, medical supplies, and equipment that are used in palliative care.

Home Health Services may also provide extra help with dressing, bathing and personal care based on your situation. Talk to your health care team and social worker about your needs and the availability of services in your community.

How can hospice programs support me?

Hospice is a program designed to provide palliative and emotional support in a homelike setting. Individuals receive specialized care aimed at relieving symptoms and pain. Comfort care is the primary goal of hospice programs, and your family members are encouraged to be by your side throughout this journey. Hospice services vary by community. Please speak with your doctor if you are interested in a referral to community or hospice society programs.





Will I have a choice about where I die?

Your personal, cultural and faith values will be respected at all times, as will your beliefs and wishes. It is important to talk to your health care team about your wishes and where you prefer to be at your end of life. Your health care team will try to accommodate your wishes.



End of Life Care

Please visit the BC Government website for more information on End of Life Care:

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care>

Can I choose to die at home?

If you wish, you may choose to die at home where you feel safe and comfortable and where you can be with friends and family. Your community may have a palliative care team, hospice facility, hospice society volunteers, or a home health team who can work with your doctor and other services in your community to care for you at home. You may want to make a plan with your family doctor so you are clear about what will happen. Also, share the plan with your family and friends to prepare them for what to do at the time of your death.

How do I plan for a home death?

Your home health nurse and family doctor are often the best people to assist you with planning for a home death. Local hospice society groups and palliative care teams can also be helpful.

Two documents must be completed by your doctor if you chose to die at home:

- NO CARDIOPULMONARY RESUSCITATION (DNR) – MEDICAL ORDER
- NOTIFICATION OF EXPECTED DEATH

The first form must be completed by a doctor to ensure no effort will be made to revive you prior to your death, in accordance with your wishes.

The second form must also be completed by a doctor after discussion with you and your family. It allows the doctor to notify your chosen funeral home of your anticipated death.

After death has occurred, the funeral home will transport your body with the consent of the person authorized to make this decision (this may be a family member or a friend).

If this notification form is completed, your family and the funeral home do not need to wait for a physician or nurse to come to the home to officially pronounce the death.

It is also important to confirm the funeral home is able to come to your home on a 24-hour basis and to determine how they can be contacted outside of regular hours.

Can I choose to die in a residential care facility?

A residential care facility is a place for people who need continual care and help with daily living. These facilities offer help for people with a range of chronic conditions. Nurses and aides are available 24 hours a day. Some residential care facilities also offer respite. In some residential facilities there are beds designated for hospice care.

Dying in residential care may be comforting, mainly if it has been your home for some time and you are familiar with the staff, who can help to make you comfortable.

Ensure that your residential care facility has a copy of your Advance Care Plan (ACP). Talk to your care providers about avoiding an unnecessary transfer to hospital at the end of life if that is your wish.

Can I choose to die in hospital or in a palliative care unit or in a designated hospice?

It may be appropriate for you to die in hospital or in a hospice for many reasons. Perhaps you require specialized nursing care, feel comfortable with the staff or worry about burdening your family. If you are already admitted to hospital, you may choose to remain there. You may have strong relationships with staff, which can be very comforting during this time of uncertainty.

While admitted to hospital, it is possible you will be transferred to a palliative care unit or hospice bed. A palliative care unit is a hospital facility or ward specially staffed and designed to provide comfort care for patients at their end of life. A hospice may be a separate facility from the hospital, it may be within a residential facility, or a wing of a hospital.

What is a medical certificate of death?

The funeral home must have the medical certificate of death before burial or cremation. The medical certificate of death and other information will be sent to the provincial Vital Statistics Agency,

which then issues a death certificate. Your doctor must complete this certificate after your death.

The death certificate is the official registration of death and contains the individual's full name, gender, date of death, place of death, place of birth, resident province, state or country, registration number, and date of registration. It does not include the cause of death. The death certificate is required for settling your legal and business affairs after death. There may be a fee for obtaining this document.

Can I choose the funeral home or memorial society?

It is up to you to choose a funeral home or memorial society. Your religious advisor and social worker may be able to assist you. When you have made your choice, the funeral director will ask your loved one to sign a release form so they can bring the body to the funeral home. Making contact with someone from the funeral home of your choice in advance is appropriate.



Note:

There are some communities in British Columbia without a funeral home. It is essential that these situations be discussed between you, your family, and your doctor, and that suitable arrangements are made.



What is MAiD?

Medical Assistance in Dying (MAiD) became legal in Canada on June 17, 2016, and is an available option for patients as part of end-of-life care. MAiD occurs when an authorized doctor or nurse practitioner provides or administers medication that intentionally brings about a person's death, at that person's request. This service is available to patients 18 years of age or older in all health authorities. The law sets out the eligibility requirements and processes under which MAiD can be provided. If a patient has a serious and irreversible medical condition, in the advanced state of decline that cannot be reversed, and natural death has become reasonably likely, the patient may be eligible. It is important to know that a patient must maintain mental capacity in order to give informed consent throughout the process, including the final moment when MAiD is provided.



Supporting you through the process of stopping dialysis

We understand that deciding to stop dialysis can be a challenging topic to think about and further reflection and discussions are often needed with your dialysis care team, family, and care partners. Your health care team can help you on this journey and will support you through this time of uncertainty. The next few pages provide a checklist. This is a guide and is only meant to assist you feeling prepared. Your dialysis team is also available to answer any questions you may have.

Checklist – Preparing to Stop Dialysis

As you consider stopping your dialysis treatment, there may be many things for you to think through. The purpose of this checklist is to help guide you through the process. And it all starts by having you think about what is most important to you.

Write down everything that seems important to you as you consider your end of life. Have you discussed these things with your family or healthcare team?

Some further points to consider when preparing to stop dialysis treatment:

- Are you registered with Home and Community Care?**
This is often required to be registered for hospice care. Your health care team can help you register for this service.

- Are you registered for BC Palliative Care Benefits?**
BC Palliative Care Benefits cover certain drugs, medical supplies, and equipment used in palliative care. Talk to your doctor or healthcare team about your eligibility for this benefit. For more information on Palliative Care Benefits, go to: <https://www2.gov.bc.ca/assets/gov/health/health-drug-coverage/pharmacare/palliative-patientinfo.pdf>

Do you have an Advance Care Plan?

For more information Advance Care Planning, refer to:

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning?keyword=advance&keyword=care&keyword=plan>

Do you have a Substitute Decision Maker?

Is your Substitute Decision Maker aware of your wishes?

For more information on substitute decision-making, go to:

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/financial-legal-matters/substitute-decision-making>

Are your family members aware of where you keep your Advance Care Planning documents?

Is your will and financial power of attorney up to date?

For more information on Estate Planning, go to:

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/financial-legal-matters/wills-and-estate-planning>

Do your family members know where your will is located?

Do you have any worries about symptoms & pain that you would like addressed by your healthcare team?

Ask about how you can be kept comfortable with symptom control and management (e.g. pain control) in advance.

To help with symptom control discussions, refer to the My Symptom Checklist:

BCRenalAgency.ca ► [Health Info](#) ► [Managing my Care](#) ► [Symptom Assessment and Management](#)

Have you discussed with your doctor a No CPR (DNR) Order and Medical Order for Scope of Treatment Form (MOST)?

The No CPR (DNR) is a medical order signed by a doctor instructing health care workers not to perform CPR on you, but instead to allow you to die naturally and in comfort.

The MOST form is used in an emergency when you can not speak for yourself and no substitute decision maker is available. The MOST form indicates to the health care team the kind of care which you have indicated you wish to receive and they can use it to discuss your plan of care.

Have you considered where you might feel most comfortable receiving care when dying?

It is important for you, your family, and your healthcare team to know where you would like to be at your end of life. Options include at home, residential facility, hospital or in hospice.

Would you prefer to die at home?

If so, the following forms must be completed by your doctor.

- NO CARDIOPULMONARY RESUSCITATION – MEDICAL ORDER
<https://www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf>
- NOTIFICATION OF EXPECTED DEATH AT HOME
<https://www2.gov.bc.ca/assets/gov/health/forms/3987fil.pdf>

You may want to ask what services will be available to when you are at home.

For more information about planned deaths at home, visit the BC government's website for Expected/Planned Home Deaths at: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/expected-planned-home-deaths>

- Have you talked to your home dialysis team about removing your dialysis machine?** Your team will be able to help with the pick-up and removal of your dialysis machine from your home.
- Have you made funeral arrangements?** Have you decided whether you want to be buried or cremated?
- Do you have any religious beliefs or cultural considerations that your family and healthcare team should know about?** In the hospital setting, there are Spiritual Care Practitioners & Aboriginal Patient Navigators. Contact your health care team if you wish to speak someone.
- Are there any family members or friends you wish to contact before stopping dialysis?**
- Do you or your family need psychological or emotional counseling or support?** Contact your kidney social worker to discuss this type of support.

There are benefits for eligible family members who wish to provide care to a loved one nearing end of life.

For more information, talk to your health care team or visit:

Compassionate Benefits

<https://www.canada.ca/en/services/benefits/ei/caregiving.html>

Income Security

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/financial-legal-matters/income-security-programs>

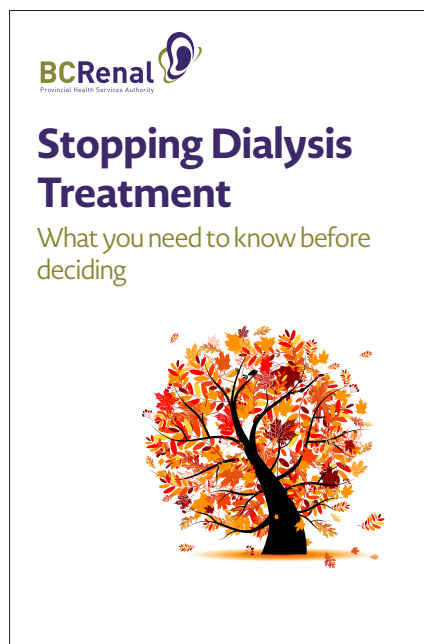
Funeral Costs

<https://www2.gov.bc.ca/gov/content/governments/policies-for-government/bcea-policy-and-procedure-manual/general-supplements-and-programs/funeral-costs>

- Do you care for your spouse or another member of your family?** Have you considered who will continue care for your family member?
- Do you have children under 19 years of age?** Have you made legal arrangements for their guardianship and future care?
- Have you made arrangements for the care of your pets?** Visit the following website for more information on pet adoption: <https://spca.bc.ca/faqs/relative-died-pet/>

You are not alone on this journey. Your dialysis team will support you through this time and be available to assist in your end-of-life transition.

Another brochure you may find useful:



To view and download, visit:

BCRenalAgency.ca ► [Health Info](#) ► [Managing My Care](#)
► [Palliative Care](#)

Produced by:




BC Renal


Phone: 604-875-7340

Email: bcpra@bcpra.ca

Web: BCRenalAgency.ca

 [Facebook.com/BCRenalAgency](https://www.facebook.com/BCRenalAgency)

 [@BCRenalAgency](https://twitter.com/BCRenalAgency)

 [Youtube.com/BCRenalAgency](https://www.youtube.com/BCRenalAgency)