

# Transitioning to Conservative Care

Patient Guide





**You have decided, with the support of your kidney care team, to choose conservative care. This guide provides information to help you prepare for a smooth transition through the steps of conservative care.**

Transitioning to conservative care has six steps. During each step your health care team will provide support. The amount of time you spend at each step will depend on your health and the recommendations of your health care team.

## Six steps to transitioning to conservative care



## What is Conservative Care?



Conservative care, sometimes called conservative kidney management (CKM) or supportive kidney care, focuses on treating the symptoms of kidney failure to make you feel as well as possible. It does **not** treat the causes or attempt to cure kidney failure. Although conservative care does not include dialysis or transplant, it does include all of the other parts of kidney care and support from your team.

# Step 1: I have chosen conservative care



## What to expect

Throughout your journey and during each step, your kidney care team works to understand your needs and provide you with relief from symptoms. The team will support you for as long as you choose. Alternatively, you may want your family doctor to care for you. The choice is up to you.

Discuss with your kidney care team what choosing conservative care will mean for you day to day. Over time, you may wish to speak to

your team about reducing your clinic visits and lab work. If a test, medication or diet restriction doesn't make you feel better or is too difficult, discuss with your team if you should continue with it. Conservative care offers you time to spend doing what matters most to you. You may not want the interruption of medical procedures, blood work or clinic visits.

Managing symptoms and the side effects that come with kidney failure can be difficult. It is important to let your nurse, doctor or healthcare team know if you have any symptoms or if your symptoms are worsening or causing you distress. Your kidney care team may use assessment tools to check on your symptoms.

Common symptoms include:

- Restless legs
- Nausea and vomiting
- Fatigue/tiredness
- Itchy skin
- Swelling
- Shortness of breath

Your kidney care team can work with you to make sure these symptoms are manageable for you.





BC Renal has developed symptom management materials to help you communicate how you are feeling to your care team and to provide strategies for resolving symptoms. Visit: [BCRenalAgency.ca](https://BCRenalAgency.ca) → Health Info → Managing my Care → Symptom Assessment and Management

### Important Decisions in this Step:

- Do I want to continue to have my blood work checked on a regular basis?
- Are all of my medications necessary at this time?
- How would I like my loved ones to be involved?



### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- What can I expect as my kidneys decline?
- Am I able to change my mind and start dialysis?
- Will I continue doing monthly blood work? And if so, how often?
- What type of care do I receive if I chose conservative care?
- How will the kidney care team be involved in my care?
- How will my primary care provider be involved?
- How will information between the kidney care team and my primary care provider be shared?
- How will my loved ones be involved in this process?
- Will I have uncomfortable symptoms?
- How often will I need to come to clinic?
- Will I be able to eat and drink what I would like?
- Will my medications be changed?
- Will changes in my health condition impact my quality of life?

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2



3



4



5



6



## Step 2: Managing well with conservative care



### What to expect

Managing well with conservative care means focusing on the things that matter most to you. That may mean spending time with loved ones, or doing the things that bring you joy. This is often referred to as quality of life as it concerns your general well-being and satisfaction with life.

Your kidney care will continue as it always has with clinic visits with your kidney care team. Working with your team, your kidney disease will be managed without dialysis. Every conservative

care management plan is different and is individualized. Depending on your needs and preferences, your care plan may include:

- Medications and lifestyle choices to protect your kidneys and slow down the progression of your kidney disease if possible
- Monitoring and treating your symptoms
- Regular communication between you and your healthcare team
- Psychological support
- Social work support: regular check-ins to ensure you feel supported and connected to community resources as needed
- Support for you and your family
- Sensitivity to your cultural and spiritual beliefs

### What should I focus on during this stage?

When you choose conservative care you can focus on whatever is important to you. That said, your kidney care team can make suggestions for managing your disease as well, and as long, as possible.



## Diet

Eating a healthy diet can help you stay well when your kidneys aren't working properly. As your kidney function decreases, your appetite may also decrease. You may be encouraged to limit certain foods such as those high in potassium, phosphorus or sodium. Your kidney care team can help you to make a plan that fits your needs.

## Fluids

As kidney function decreases, your kidneys may not make as much urine as before, and your body may get overloaded with fluid. Some people need to limit their fluids, while others can drink as much as they want. If you have symptoms like swelling and shortness of breath, talk to your kidney care team about how much fluid you should drink. Some people have to take medicine (water pills) to help manage fluids in their body.

## Medicine

You may wonder if you need to continue taking certain medications. Discuss this with your kidney care team to create a plan that works for you and your symptoms.

## Blood Pressure

It is important for most people with chronic kidney disease to manage their blood pressure so it doesn't get too high. However, if you find daily monitoring of your blood pressure becomes too much, discuss your options with your kidney care team

### Important Decisions in this Step:

The main thing to think about at this stage is:

#### *What is most important to me right now?*

- Slowing disease progression?
- Not taking so many pills?
- Eating whatever I want?
- Not spending so much time at care appointments?
- **Or anything else that is important to you! Whatever you choose to prioritize is the right choice!**

Talking about your preferences with your care team will help in creating a care plan that puts your priorities first.





### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- What foods are healthy for me and which should I limit?
- How can I manage a poor appetite? Should I use supplement drinks?
- What fluid recommendations should I follow?
- How much water and other fluids should I drink?
- Do I have to keep taking all of my medicines? Are any of my medicines harmful to my kidneys?
- Do I need to continue with my daily health checks? (e.g. blood pressure, blood sugar, etc.)
- If I do continue to monitor my blood pressure, what should my numbers be? How often should I check these numbers at home?
- If I do continue to monitor my blood sugar, what should my numbers be? How often should I check these numbers at home?

## Step 3: Symptom Management



### What to expect

As your kidney function declines, there are common symptoms you may experience. These could include nausea, poor appetite, itchy skin (pruritus), sleep difficulties, anxiety/depression and trouble breathing. You might have pain from other conditions as well. Your kidney care team can give you more information on your symptoms and help you manage them.

You may also want to refer to the BC Renal website, which offers many resources to help with symptom management.



Visit: [BCRenalAgency.ca](https://BCRenalAgency.ca) → Health Info → Managing my Care → Symptom Assessment and Management





Having a plan to relieve distressing symptoms if they occur can be comforting. Your care team can help you make a plan showing steps to take and who to contact if you experience unpleasant symptoms. Here are some important things to include in your care plan:

### Pain

Steps to take:

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Who to contact:

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### Shortness of Breath

Steps to take:

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Who to contact:

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### Nausea/Poor Appetite

Steps to take:

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Who to contact:

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### Itchy Skin (Pruritus)

Steps to take:

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Who to contact:

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### High Potassium

Steps to take:

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Who to contact:

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### Sleep Disturbances

Steps to take:

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Who to contact:

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### Anxiety/Depression

Steps to take:

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Who to contact:

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Other: \_\_\_\_\_

Steps to take:

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Who to contact:

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## When to call your team

If a symptom is getting worse and you are uncomfortable or uncertain what to do, call the healthcare team member listed in your health care plan. You may be instructed to call an ambulance or emergency response team who will work with your doctor to attempt to treat your symptoms, but it is always up to you about how to proceed with your care.

This table will help to organize your team members and contact information. You may also want to share this information with your loved ones.

## Team Members and Contact Information

Family Physician: \_\_\_\_\_

Kidney Care Team: \_\_\_\_\_

Home Health Team: \_\_\_\_\_

Pharmacy: \_\_\_\_\_

Who to call after hours: \_\_\_\_\_

\_\_\_\_\_



## Important Decisions in this Step:

- Do I know what to do if my symptoms get worse?
- Do I want someone to call the emergency response team (i.e. ambulance) if my symptoms continue to get worse, or would I like to manage my symptoms at home?
- Do I want to be admitted to the hospital if my symptoms get worse?
- Are there any worries about symptoms and/or pain that I would like addressed by my kidney care team?





### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- Who do I call first if I have a question?
- Who will I call after hours if I need assistance?
- What type of support is available in my community?
- How do I access the support in my community?
- Do any of my care providers come to my home?

## Step 4: Actively Planning for the Future

### What to expect

At this time, your kidney care team will talk with you about your illness, your goals and wishes, and planning for the future. You may already have an Advance Care Plan that will need to be reviewed as an important part of your care. The kidney care team will start talking about this when you are feeling well. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future.

Thinking about and sharing your wishes will give you more control over the care you would like to receive. Knowing what your wishes are will also ease the burden for your family if you are unable to speak for yourself.

Your wishes are also important to your kidney care team. We want to work with you to plan your care around what matters MOST to YOU.



To let us know more about you and your wishes, please fill out the following:

**My understanding of my health condition(s):**

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**I want more information about the likely future of my health condition:**

Yes     No

**These are my most important goals as I live with my health condition:**

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**These are my biggest fears and worries about the future with my health:**

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**This is what gives me strength as I think about my future with my illness:**

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**These are abilities in my daily life that are critical to me that I cannot imagine living without:**

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**If I become sicker, to gain more time I would be willing to go through:**

Tests     Treatments     Hospital Stay  
 Other \_\_\_\_\_

**These family members/friends are aware of my wishes:**

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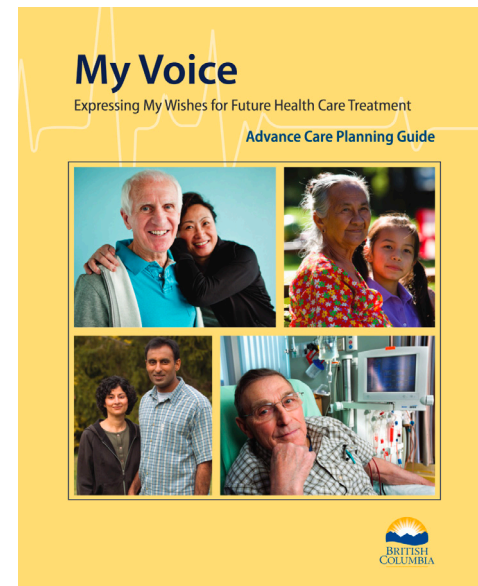
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Thinking about and sharing your wishes will give you more control over the care you get. It will also help prepare your loved ones to make decisions for you if you are unable to make decisions at some point in the future.

Talking about the future won't change the plans you have made so far about your treatment, unless you want to. We will keep providing the best possible care to control your disease.

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will always be here to support you and answer your questions so that you can make informed decisions.



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, a personal planning resource centre at: [nidus.ca](http://nidus.ca)

Please speak to your kidney social worker for more information.



## Important Decisions in this Step:

- What is most important to me at this time?
- What brings me joy?
- What am I willing to go through to gain more time?
- Are there any spiritual or religious practices that are important to me as I come to the end of my life?
- Where would I like to be cared for at the end of my life? (home, hospice residence, palliative care unit, hospital)
- If these services are not available in my community, where would I like to be cared for at the end of my life?
- Is there anything I want my family or health care team to know about me?
- If I can't speak for myself, who will speak for me (e.g. a substitute decision maker)?



### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- Can you tell me what lies ahead for me with my illness?
- Can you help me plan what I need to do so I am ready for what lies ahead?
- Can we discuss what I am willing to go through to gain more time?
- Can you help me identify the things that are crucial to my life, that I can't imagine living without?



## Step 5: Later stages of conservative care



### What to expect

As your kidney function declines, your kidneys are less able to do what your body needs. You may start to experience more symptoms of kidney failure. This typically happens gradually; in general, your kidneys don't fail all at once. This is often a slow process.

As your kidneys slowly start to fail, the waste products are no longer filtered out of your blood. As these waste products build up inside of your body, it becomes harder for your other body organs to work properly. As this happens, most

people become gradually sleepier until they are no longer able to wake up.

As all of this happens, your kidney care team or family doctor will continue to support you, manage your symptoms and monitor your health. As an added layer of support, your kidney care team may refer you to palliative care, which is specialized health care for people in an advanced stage of a life-limiting illness.

### Important Decisions in this Step:

- Does my health care team know my wishes concerning my Do Not Resuscitate (No CPR/ DNR) status?
- Have I made arrangements for the care of my spouse or other members of my family?
- Have legal arrangements been made for the guardianship and future care of my children under the age of 19?
- Does my family need psychological or emotional counselling or support?
- Have I made arrangements for my pets?





### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- What care is available in my community?
- Will home care be available for me as I near my end of life?
- Can I choose to die at home? If so, what supports are available as my health declines?
- Is my kidney care team available to me when I am close to the end of my life?
- What might I expect in my final days?
- What services are included in palliative care?
- Have I been referred for palliative care benefits?
- How will home and community care be organized?
- Can I be supported at home?
- How will my family be supported?

## Step 6: Approaching end of life



### What can I expect?

As end-of-life approaches, your kidney care team or family doctor will work closely with a specialized palliative care team to offer medical assistance and emotional support for you and your family.

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

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





Palliative care helps patients to achieve the best possible quality of life right up to the end of life. This type of care provides comfort, pain relief and reduced suffering. The palliative care team will work with you and your family and will bring together the supports you may need as your health declines.

Palliative care includes:

- Pain management
- Symptom management
- Social, psychological, emotional and spiritual support
- Caregiver support

Your personal values and your cultural and spiritual beliefs and practices will be respected at all times. Talk to your palliative care team about any final wishes and where you prefer to be at your end of life.



The BC Renal website has a number of resources to help you choose the best care in your community and will link you to your health authority website. Visit:

[BCRenalAgency.ca](https://www.bcrenalagency.ca) ➔ Health Info  
➔ Palliative Care ➔ Local ACP and  
Palliative Care Resources

## Important Decisions In This Step

- Are there any loved ones or friends I would like to contact before dying?
- Have I have chosen where I will feel most comfortable receiving care at the end of my life? (Hospice residence, home, residential care, hospital, palliative care unit?) \*\*\* If you are unsure, discuss these options with your family doctor or social worker.



### QUESTIONS TO ASK MY KIDNEY CARE TEAM

- How will the kidney care team be involved at the end of my life?
- Who can I speak with if my family needs financial assistance?
- Is there financial compensation available to my family if they wish to take time away from work to support me while I am critically ill and nearing end-of-life?
- If I chose a home death, what forms need to be completed by my family doctor?










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