



# CONSERVATIVE

## KIDNEY MANAGEMENT

Living well without dialysis

[www.CKMcare.com](http://www.CKMcare.com)



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We would like to dedicate this work to the patients and family members who we have the privilege of caring for, and together shaping quality healthcare for generations to come.



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**Section 1:  
Thinking about Conservative  
Kidney Management (CKM)**

## **What is conservative kidney management (CKM)?**

CKM is a treatment option for managing kidney disease. It involves:

- treating symptoms of kidney disease.
- preventing or managing problems.
- protecting and maintaining the remaining kidney function.
- supportive medical and psychosocial care when needed.
- helping people plan for the future.

CKM doesn't include dialysis, but it does include all of the other parts of kidney care and support. The goals of CKM are for you to live well without dialysis, so you'll be as comfortable as possible and have a good quality of life.

## **Why choose CKM?**

Dialysis may not help everyone live longer or improve their quality of life. For some people, the side effects of dialysis may even lower their quality of life or make them feel worse. Dialysis won't treat other medical problems (e.g., diabetes, heart conditions, arthritis, pain).

Some people might feel that for them, the burden of dialysis isn't worth the benefits. They might prefer non-dialysis care.

We know that some people aren't as likely to do well on dialysis, which means they aren't likely to live longer or feel better. Often, these are people who:

- have other serious medical problems (especially heart disease and/or dementia).
- need lots of help with activities like bathing, dressing, and moving around.

CKM may be a better treatment for some people.

## **What can help me decide if CKM is right for me?**

As your kidney function declines, one of your biggest choices is whether to get dialysis or conservative kidney management (CKM).

It's your choice whether to have CKM or dialysis.

There is an online Patient Decision Aid (PDA) available at [www.ckmcare.com](http://www.ckmcare.com) to help guide your decision. The interactive tool can be used to help you decide if CKM or dialysis is right for you. You can use it to talk with your healthcare team and loved ones about your decision.

The decision-making tool takes into account such things as your values and beliefs, where you are living, your age, your current health and control of personal time. The PDA focuses on: quality of life, prognosis, treatment options and chances of survival.

## **What can I expect if I choose CKM?**

If you choose CKM, you'll:

- talk about what's most important to you (goals).
- get treatment to help you reach your goals.
- learn about what symptoms to expect as your kidney's change and how to manage them.
- have your symptoms checked regularly and treated if needed.
- have bloodwork done only as needed.
- take medicine as needed.
- talk about where you want to live as your kidney disease progresses.
- work on an action plan, so you don't have to go to the emergency department or hospital unless you really need to.
- talk with your family/friends and healthcare team about your wishes for treatment choices in the future (advance care planning).
- learn about resources in your community to support you and your family/friends.
- have support from your healthcare team from diagnosis through to dying and death.

## **After I choose CKM, can I change my mind?**

Yes. The decision is yours. Your healthcare team will do everything they can to make sure you know what stage of illness you are at, how different treatments may affect your health and how you feel, and that you know about all of your treatment choices. We want to support you in the treatment choice that's best for you.

## **How long will I live while receiving CKM?**

Nobody knows the answer to this question. Many factors affect how long you'll live. Depending on how fast your kidneys change, you may have weeks, months, or years to live. Some factors that affect how long you'll live include:

- your kidney function/glomerular filtration rate (GFR).
- other health problems (e.g., diabetes, heart disease).
- your lifestyle (e.g., weight, exercise, diet, blood pressure).
- your overall health (physical and mental health).

## **What kind of support will my family and I receive?**

For most people, it's important to involve family or important friends (your support people) when deciding if CKM is the right choice for them. It's also important to ask your healthcare team for information and support when you need it.

If you wish, a meeting can be arranged with you, your support people, your doctor, social worker, and other healthcare providers. This meeting is to support you, answer questions, and talk about concerns. For many people, knowing their support people understand their wishes is a relief and gives them peace of mind.

Reaching your decision about CKM or talking about the final stages of kidney disease may be very emotional for you and your support people. Everyone reacts differently when they're told their kidneys are failing—this is normal and expected.





## **Who will be on my healthcare team?**

Everyone's healthcare team is different, depending on where they live and where they've been receiving kidney care.

If you've been going to a chronic kidney disease clinic, you might keep going to this clinic and see your nephrology team. Some people with kidney disease don't go to a kidney clinic, instead their kidney care is managed by a family doctor or nurse practitioner (NP).

Your healthcare team may include dietitians, social workers, pharmacists, spiritual health practitioners, nurses, NPs, and doctors. They'll respect your values, choices, and independence.

### ***Dietitians***

Your dietitian will help with all your food concerns. The kidney diet is not always easy to follow and your dietitian can help you make good food choices to help manage your kidney symptoms.

### ***Social Workers***

Social workers can help you and your family cope with the stress of having kidney disease. Social workers can connect you to services that can help with finances, housing, transportation, and how you feel.

### ***Pharmacists***

Pharmacists help you manage your medicine and make sure what you're taking is safe for your kidneys. If you have questions about medicine (e.g., side effects), talk to your pharmacist. It's a good idea to tell your community pharmacist about your kidney disease. If you need help taking your medicine, ask about blister packs, pill boxes, and reminders.

### ***Spiritual Health Practitioners***

Spiritual health practitioners offer spiritual and emotional support to people and their families/friends. If you're interested in contacting a spiritual health practitioner, talk to your healthcare provider or connect with groups in your community. Spiritual care services (SCS) can help by:

- listening to questions about identity, meaning, and beliefs.

- helping you reflect on your belief system, faith tradition, and/or religious resources.
- offering support and rituals as needed.

Spiritual care is respectful, compassionate, objective, and non-judgmental for people from all faith communities or people not connected to a faith group.

### ***Nurses***

A nurse is often your first contact for concerns and can refer you to other members of the healthcare team. If you go to a kidney clinic, you'll have a nurse as your case manager whom you can call for help and information. Your case manager will help you manage symptoms of kidney disease, try to help you feel better, and keep track of your bloodwork.

You may have a Home Care nurse or case manager who sees you at home and works with your family doctor and kidney team. Home care is usually very helpful for people who want to stay at home for as long as they can.

### ***Nurse Practitioners***

Nurse Practitioners (NP) are nurses with extra training. They work in many different places and may help with your kidney care. Nurse practitioners can make full assessments, and diagnose and manage many symptoms. They can order tests, do procedures, and prescribe medicine.

### ***Doctors***

Your family doctor is an important member of your healthcare team and will keep seeing you. If you don't go to a kidney clinic, your family doctor will likely manage your kidney care. They can consult with a kidney doctor if needed.

You may also have a kidney doctor (nephrologist) who will keep seeing you to help your kidneys work the best they can and to help manage symptoms.







**Section 2:  
Now That I've Chosen  
Conservative Kidney  
Management (CKM)**

## **How can I look after my kidney function?**

Many people who choose CKM live for months or even years. Your healthcare team might suggest ways to protect and maintain your kidney function, and if at all possible, slow the progression of your kidney disease.

### ***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.

Some people with kidney disease are encouraged to limit certain foods (e.g., those with high potassium, phosphorus, or sodium). This can make it hard to enjoy eating, but some foods can make symptoms worse (e.g., phosphorus can cause itching, sodium can cause swelling or shortness of breath).

With CKM, the goal is to help you feel well and enjoy your meals. You may have diet restrictions, but only if they help you to feel better. Your diet also depends on other factors like the stage of your kidney disease or if you have other health problems.

### ***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, ask your healthcare providers (e.g., dietitian) how much fluid you can drink.

Some people have to take medicine (also called water pills) to help manage fluids in the body.

### ***Medicine***

Your kidneys can be damaged by certain types of medicine. Check with your healthcare provider before you take any new medicine. It's important to keep an updated list of your medicine so your healthcare team knows what you take—be sure to include over-the-counter medicine, vitamins, supplements, and herbal products.

You and your support people will be involved in treatment decisions. If you have side effects or questions about your treatment, talk to your healthcare team. Please also talk to them if you're having concerns with:

- affording your medicine.
- taking too many pills.
- swallowing your pills.
- knowing or remembering when to take pills.

### ***Blood Pressure***

It's important for most people with chronic kidney disease to manage their blood pressure so it doesn't get too high. This can help protect your kidneys and health.

It's also important that your blood pressure doesn't go too low. Low blood pressure or blood pressure that drops quickly when you stand up can be dangerous and may cause you to fall.

For this reason, not having very low blood pressure may be more important than having very strict blood pressure control.

## How do I feel?

It's important to talk to your healthcare team about how you're feeling, physically and emotionally. Here are some questions to think about before you see your healthcare providers.

What have your main problems or concerns been over the past week?

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Have you been having any other problems (e.g., personal, financial) related to your kidney disease?

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Have you had as much information as you want?

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Have you been feeling anxious or worried about your illness or treatment?

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## **What are the symptoms of kidney disease, and can they be managed?**

As your kidney function decreases, there are some common symptoms you might have including:

- itchiness
- tiredness
- trouble sleeping
- restless legs
- nausea or vomiting
- shortness of breath
- pain (usually caused by other health problems)
- swelling

Your healthcare team will help you manage your symptoms as much as possible. It's important to let your nurse, doctor or healthcare team know if you are having any symptoms or if your symptoms are worsening or distressing to you. You can read more about symptoms in the next few pages. Dialysis does not necessarily fix these symptoms – people on dialysis tend to have these symptoms too.

Healthcare providers may use assessment tools to learn about your symptoms.

## Pain

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Pain is usually due to a health issue that's hard to treat or can't be cured. When not treated, it can take over your life, making you feel depressed, anxious, and/or angry. It can also affect your sleep, relationships, activity level, and how you enjoy life.

Managing pain works best when you play an active role. It usually includes a combination of treatments, such as physiotherapy, exercise, and medicine. You may have to try a few treatments before you find the one that works the best for you. Learning to relax and to change negative thinking can help you cope with pain. It's important to stay in touch with your care provider to make sure your pain is being managed.

### What tips can I try at home?

- **Pace yourself.** Break larger jobs into small jobs or save the harder jobs for when you have less pain. Rest often during the activity.
- **Keep moving.** Do gentle exercises like walking, swimming, and riding the stationary bike every day. Stay flexible by stretching every day.
- **Relaxation techniques.** Ask if someone on your healthcare team can help you get started. You can also learn some of these on your own. Some techniques include:
  - Deep breathing exercises: Slow your breathing to the point where you are as relaxed in your breathing as possible. Breaths should be deep and fill your lungs.
  - Meditation: Sit or lie in a comfortable position for 20 minutes. Be aware of your breathing, your sensations (including your pain), your thoughts, and feelings.
  - Guided Imagery: Form mental images to take a visual journey to a peaceful, calming place or situation.
  - Yoga: Can relax your breathing, ease muscle tension, and energize your mind and body.
  - Massage: Helps reduce tension and pain.
- **Think positively.** Positive thinking can ease pain.
- **Do an activity or hobby** you enjoy.
- **Get a good night's sleep.** Pain may make you tired. Pain may be worse if you don't get enough sleep. Talk to your doctor if pain is causing sleep problems.
- **Keep a pain diary.** Keep a record of your pain levels throughout the day and how your pain affects your mood, activities, sleep. Sharing your diary with your care provider can help your provider decide the best way to manage your pain.

## What treatment choices do I have?

Your care provider may suggest treatment options such as physiotherapy, acupuncture, acupressure, or TENS (transcutaneous electrical nerve stimulation).

If you take pain medicine, let your care provider know how it's working for you or if you're having side effects (such as constipation or drowsiness). Take your pain medicine as prescribed so that your pain doesn't get out of control.

Talk to your care provider before taking over-the-counter medicine.

## Tiredness

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It's common to feel tired when you have kidney disease. Even if you rest or get lots of sleep, you can still feel exhausted and have no energy. Fatigue can have many causes, including low iron or vitamin D, and a build-up of toxins in your body caused by your failing kidneys. There's no easy way to deal with fatigue. Instead, you may want to try different ways to try to improve or save your energy—you may need to be a bit creative in how you go about your day.

Your healthcare team may be able to help you apply for a parking placard. This is a special tag for your car so you won't have to walk as far when you go out. You may also be able to have your bloodwork done at home.

## What are some tips to improve my energy?

- Exercise can help (speak with your care provider).
- Ask your care provider about an eating plan that's best for you. You can ask for a referral to a dietitian.
- Ask your healthcare team how you can get started with using relaxation therapy or stress management techniques.
- Try complementary treatments, such as acupressure or acupuncture.

## **What are some tips to conserve my energy?**

### ***Daily Living***

- Sit down to bathe.
- Wear a terry bathrobe to dry off.
- Installing bars, not just in the bathroom, but any place where you might need to reach for extra support while moving around, such as the kitchen, bedroom, laundry room.
- Place chairs around your home so you can stop and rest (for example, at the top and bottom of the stairs).
- Ask your Home Care provider about equipment in the house to make life easier such as a walker, cane, commode, urinal, etc.
- Try to rest before you get too tired.

### ***Housekeeping***

- Spread tasks over the week.
- Do housework sitting down if possible (for example, sit down to iron).
- Ask someone to help you with shopping and laundry.
- Drag or slide heavy items instead of lifting them.
- Keep a small trash can in each room.

### ***Shopping***

- Organize your list by aisle.
- Use a grocery cart for support.
- Shop at less busy times.
- Ask for help bringing your groceries to the car.

### ***Preparing Meals***

- Prepare meals sitting down.
- Soak dishes instead of scrubbing and let dishes air dry.
- Make double portions and freeze half.
- Keep items you use often near you and in easy reach (for example, keep a plate, cup, and cutler on the counter)

*Adapted from:*

- *99 Questions (and more) about Hospice Palliative Care, Appendix E*
- [www.kidney.org/transplantation/transaction/TC/fall14/11-tips-save-energy-changing-your-daily-routines](http://www.kidney.org/transplantation/transaction/TC/fall14/11-tips-save-energy-changing-your-daily-routines)

## Itch

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Itch is common in kidney disease. Only one area may itch or you might feel itchy all over. It can also be caused by skin sensitivities and allergies. Scratching can cause breaks in the skin, bleeding, and infection. Tell your care provider if you're having a problem with itching.

### What tips can I try?

#### *Home*

- Keep your home cool and humid, especially in the winter.
- Use mild detergents and make sure clothes and bedding are rinsed well.
- Wear loose, lightweight cotton clothing and use cotton bed sheets.

#### *Diet*

Kidney disease can cause high levels of phosphorus, which can cause itching. If you wish, you can speak with your care provider and/or dietitian about limiting phosphorus in your diet or about taking medicine to lower your phosphorus.

#### *Personal Care*

- Bathe for at least 15 minutes every day in lukewarm water. Baths are preferred to showers.
- Soaps and body washes can irritate your skin. Use gentle cleansers instead such as CeraVe® or Cetaphil® and use them only on the parts of your body that really need cleaning (such as sweaty areas like armpits and groin). Otherwise, just use water to wash.
- Gently pat your skin to dry. Moisturize within 2 minutes of getting out. Your skin should still be damp. Use hypoallergenic moisturizers with ceramides (such as CeraVe®) that have no scents or other additives.
- Avoid using creams on areas of broken skin. Avoid scratching – keep fingernails short, try massaging your skin rather than scratching, try wearing gloves at night.

### What treatment choices do I have?

Talk to your care provider if you're having trouble managing the itching. There are medicated creams and medicine that can help. Some over-the-counter creams or lotions, such as Gold Bond® anti-itch products might help.

Don't take over-the-counter medicine (for example, antihistamines) for your itch.

Ask your care provider about treatment options such as phototherapy or acupuncture.

## Nausea and Vomiting

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Nausea and vomiting can be an upsetting symptom of kidney disease. You can still throw up (vomit), even if you don't feel sick to your stomach (nausea). There can be many reasons for nausea and/or vomiting, such as certain medicines, being constipated, and toxins building up in your body because of your failing kidneys.

### What tips can I try at home?

Depending on the cause, there are some things you can try at home.

- Try to prevent or manage constipation.
  - Slowly increase the fibre in your diet over a few days. Don't eat all the fibre with 1 meal—spread it out over the day in your meals and snacks.
  - Eat regular meals and snacks during the day.
  - Drink fluids. Talk to your healthcare provider about how much fluid you can drink in a day.
  - Be as active as possible.
  - If you're having problems with constipation or your diet, talk to your care provider about seeing a dietitian or there may be medicine you can take.
- Eat smaller amounts of food more often, and adjust the time you eat. For example, if you often feel sick to your stomach in the morning, try eating breakfast a little later.
- Eat slowly.
- Drink fluids 30 to 60 minutes before or after meals, instead of with meals. Don't drink alcohol.
- Stay away from foods that are greasy, spicy, or very sweet.
- Keep the air fresh—stay away from cooking smells, scents like perfume, or smoke.
- Keep your mouth fresh. For example, brush your teeth, or use a non-alcohol mouthwash or club soda to rinse your mouth.
- Stay upright for about 1 hour after eating, as this can help with digestion.
- If you're feeling sick to your stomach, put a cool damp cloth on your forehead or the back of your neck.
- Wear loose fitting clothing.
- Think about using ginger and other complementary therapies such as relaxation, imagery, acupressure, or acupuncture.

## What treatment choices do I have?

Speak with your care provider if your nausea or vomiting is hard to manage. There's medicine you can take (either by pill or injection). Talk to your care provider before trying over-the-counter medicine.

When vomiting lasts for a long time, you can get dehydrated. If you have a Home Care professional helping with your care, be sure to tell them about your nausea or vomiting.

## Restless Legs

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Restless legs can be an annoying symptom of kidney disease. It causes an urge to move your legs when you're at rest. You may also have an uncomfortable feeling in your legs.

It's often worse in the evening or at night, which can make it hard for you to fall or stay asleep. You might notice that moving your legs makes them feel better.

Let your care provider know if you have restless legs, especially if it's affecting your everyday activities or your sleep.

## What tips I can try at home?

- Stop or cut down stimulants such as alcohol, caffeine, and nicotine to see if your symptoms go away. Don't use them in the evening, before bedtime.
- Try to keep yourself mentally busy. For example, do word or number activities like crossword puzzles or Sudoku, needlework, or video games.
- Try aerobic exercise, walking, and/or stretching (if it's safe for you).
- A gentle leg massage sometimes helps.
- Good sleep hygiene may help:
  - wake up at the same time every morning.
  - don't go to bed until you feel sleepy. Don't "try" to fall asleep.
  - try not to nap during the day.
  - use your bedroom for sleep (and sex) only.

- Learn relaxation techniques. Ask your healthcare provider about how to get started. You can also learn some of these on your own. Some techniques include:
  - progressive muscle relaxation (focus on slowly tensing and then relaxing each muscle group)
  - visualization (form mental images to take a visual journey to a peaceful, calming place or situation).
  - deep breathing.
  - music and art therapy.

## What treatment choices do I have?

Speak with your care provider if restless legs are a problem for you. Your care provider may talk about treatment options such as medicine, acupuncture, or acupressure.

If you're taking medicine for restless legs, take it **exactly** as prescribed—don't wait for your restless legs to get too bad.

## Feeling Short of Breath

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Feeling short of breath or like you can't breathe is a possible symptom of kidney disease and can be upsetting. There can be many causes: low iron levels, extra fluid in the lungs, and even being anxious. Remember that you know best how your breathing feels—you may not *look* like you're short of breath, but that doesn't mean that you don't *feel* short of breath.

## What tips can I try at home?

- Sit more upright. Using pillows to support your back may help.
- Sit near an open window.
- Sleep more upright. Sleeping in a recliner may help.
- Have a fan blow gently across your face.
- Keep the air humidified.
- Try “pursed lip” breathing—ask your care provider to show you. If it doesn't feel natural or it doesn't help, don't do it.
- Wear loose clothing, especially around your neck.
- If you take medicine for your breathing, try taking it before doing an activity that makes you feel short of breath.



- Rest often between activities that make you feel short of breath (for example, walking, washing, dressing, or talking).
- Keep surroundings as calm as possible—especially if you’re feeling anxious.
- Try meditation, mindfulness, or relaxation therapy.

## **What are some relaxation techniques?**

Some of your healthcare providers may be able to teach you relaxation techniques or you can learn some on your own. Some techniques include:

- progressive muscle relaxation (focus on slowly tensing and then relaxing each muscle group).
- visualization (form mental images to take a visual journey to a peaceful, calming place or situation).
- music and art therapy.

## **What treatment choices do I have?**

Talk to your care provider if shortness of breath is still a problem for you. You may need medicine, including oxygen, if your oxygen level is low.

Following a low-salt diet may help your breathing too, because salt affects the amount of fluid in your body. Too much fluid in your body can lead to shortness of breath. If you need more help with this, speak with a dietitian.

Sometimes when you’re very short of breath, it can feel like an emergency. Plan ahead and have a list of who you can phone and what medicine (including oxygen) you can take to help your breathing.

If you have Home Care, they may be able to help you with your shortness of breath at home. Be sure that you or your family always let the nurse, doctor or healthcare team know if you are experiencing feeling short of breath or if your symptoms are getting worse.

## Sleep

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Having trouble getting restful sleep may be a problem with kidney disease. This could be because of other issues such as itching, pain, trouble breathing, or restless legs. If you're having trouble sleeping, and if it's affecting you during the day, talk to your care provider.

### What are some tips to help me sleep?

These sleep hygiene tips may help you get more restful sleep.

- Wake up at the same time every morning.
- Don't go to bed until you feel sleepy. Don't "try" to fall asleep. If you can't sleep, go into another room and do something relaxing until you feel tired.
- Try not to nap during the day, especially later in the afternoon.
- Be in bright sunlight in the earlier part of the day and stay away from it in the evening.
- Limit or cut out caffeine and nicotine in the evening.
- Try not to eat large meals close to bedtime.
- Use your bedroom for sleep (and sex) only.
- Make sure that the room you sleep in is as comfortable as possible (including your mattress and pillow).
- Try a sound machine or a fan to block noise from inside or outside the house (white noise). Try room-darkening blinds.
- Relax before bed. Your body needs time to shift into sleep mode, so spend the last hour before bed doing a calming activity. Keep a notepad at your bedside so that if you wake up, you can write down the thought and go back to sleep, instead of thinking about it all night.
- Practice relaxation techniques. Ask your healthcare provider how to get started. You can also learn some of these on your own. Some techniques include:
  - progressive muscle relaxation (focus on slowly tensing and then relaxing each muscle group).
  - visualization (form mental images to take a visual journey to a peaceful, calming place or situation).
  - deep breathing.
  - music and art therapy.

## What are some treatment options?

Even if you're trying the sleep tips, you might still not be sleeping well. Be sure to let your care provider know. You can ask about medicine to help you sleep. Talk to your care provider before taking over-the-counter sleep medicine.

## Swelling

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Swelling is common with kidney disease. Swelling happens when there's extra fluid in your body and your body isn't balancing the fluid. You may notice you're gaining weight, have swelling in your feet and lower legs or in other places like your fingers, around your eyes, and your lower back. Shortness of breath can also be a sign that fluid is building up in your chest or lungs. Tell your healthcare provider if you have any swelling or shortness of breath. There's medicine you can take to manage this. Some changes to your diet and fluid intake might also help.

### *At Home*

- When you're sitting, elevate your swollen feet/legs on a stool to help blood flow back to your heart.
- Wear compression stockings if your doctor says you can.
- Remember to walk. This helps move fluid from your lower legs up to the rest of your body.

### *Diet*

- Don't add salt to food—use herbs, spices and salt-free seasoning instead.
- **Don't** eat canned, packaged, frozen, and bottled foods with more than 200 mg sodium per serving. You can find this information on nutrition facts labels. Common high-salt foods are canned soup, potato chips, hot dogs, deli meats, and sausage.
- Don't drink more than 6 cups (1.5 litres) of fluid a day because it can make swelling worse.
- Think about eating kidney-friendly frozen meal options from Meals on Wheels™. Ask your healthcare provider about this or and other services for meals.

## **What else can I do?**

- Know your blood pressure. It can go up with extra fluid in your body.
- If prescribed by your doctor, make sure to take your water pills (diuretics like Lasix®).
- Weigh yourself every day and keep track to see if your weight changes.



## **Section 3: Planning for the Future**

## **Planning for the Future**

Even though you may be in good health now, there's no way to know when this might change. When your symptoms get worse, it may be very 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. Planning for your future may include:

- preparing a Will.
- preparing an Enduring Power of Attorney.
- preparing a Personal Directive.
- Advance Care Planning.
- a Goals of Care Designation.

### ***Preparing a Will***

A will is a legal document which states your wishes about how your assets are divided after your death. You name a personal representative who will represent your estate after your death and carry out your wishes. Your will should be clear, legally valid, and up-to-date. A will comes into effect after you die.

### ***Preparing an Enduring Power of Attorney and Personal Directive***

An Enduring Power of Attorney and Personal Directive ensures your wishes are heard and followed while you're still alive, but because of your medical condition you can't make decisions.

An Enduring Power of Attorney is a legal document which allows you to appoint an Attorney. This is the person who you've legally named to look after your property and financial matters on your behalf if you can't in the future because of your medical condition.

A Personal Directive is a legal document that allows you to name an agent. This is the person you trust to make personal and healthcare decisions on your behalf if you can't in the future because of your medical condition. It documents your instructions for personal and healthcare decisions which you want your agent to follow. Your Personal Directive only comes into effect when you can't direct your own healthcare. A Personal Directive is a legal document, but you don't need a lawyer to complete it with you. For more information, see the next section on *Advance Care Planning*.

## ***Advance Care Planning***

Advance care planning is thinking about, talking about, and documenting your wishes for healthcare if you can't communicate or make healthcare decisions on your own. It's a process that can help you make healthcare decisions now and for the future to make sure your voice is always heard. To do this, follow these steps:

1. Think about your **values, wishes, and goals** for your healthcare and what's important to you. Ask yourself:
  - Do you have personal beliefs that influence your healthcare wishes?
  - What things do you want to be able to do to have quality of life? If you couldn't do these things, how would you feel?
  - Are there conditions under which you do or don't want a certain treatment?
  - Where would you want to be cared for?
  - Have you had past healthcare experiences when healthcare decisions had to be made? How have these experiences influenced how you want to be cared for in the future?
2. Learn about your health problem and what you may go through because of it. Learn about possible treatments and what to expect from the treatments. Learn about **types of healthcare decisions** you may need to make in the future as your health changes.
3. Choose someone to make personal and healthcare decisions and speak on your behalf. In Alberta, we call this person an **agent**. Here are some questions to think about when choosing an agent:
  - Who knows your wishes the best?
  - Do you trust this person to make healthcare decisions with your healthcare team based on your values and wishes?
  - Have you spoken to this person about your wishes? Are they willing to take on this responsibility?
  - Can this person make hard decisions under stress?
  - Can this person communicate clearly?

4. **Talk to your agent and family** about your future healthcare wishes. This is likely the most important step in advance care planning. This is because it ensures your family understands your wishes and it helps your family support your agent when carrying out your wishes. This can help avoid conflict around healthcare decision making. As your healthcare wishes may change, it's important to communicate changes with your agent.
5. Talk to your healthcare team about your wishes. You need to do this so your wishes are properly translated into a medical order, called a **Goals of Care Designation Order**. This order guides the healthcare team to care that meets your values, wishes, and goals. Once you've chosen CKM, your doctor/NP needs to write that you've chosen "not to have dialysis" on your order form.
6. When your Goals of Care Designation Order is completed, keep it in a Green Sleeve and place it on or near your fridge. The Green Sleeve is a plastic document holder that's recognized across Alberta—you can get one from your family doctor, NP, or Home Care team. Bring it with you to your appointments and if you go to the hospital. If you ever call 911, you or your family should show them your Green Sleeve.
7. Document your wishes in a **Personal Directive**. Review your Personal Directive regularly and when there's a change in your health condition. This makes sure your wishes are always up to date.

It's a good idea to speak to your healthcare team about advance care planning. A member of your healthcare team will talk about this with you and ask if you need any help or resources. They'll meet with you, your agent, and support people to talk more about advance care planning to make sure your wishes are heard and documented properly.



## Questions to Ask Yourself

How do I see my health at the moment?

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What makes my life meaningful or worthwhile?

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When I think about my future, are there things I worry about?

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What have I talked with my family about? What might I want for my future (including end of life) care?

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## What other teams might be involved in my care?

Besides your family doctor or NP, you may also meet with these teams:

- Nephrology
- Continuing Care teams like:
  - Home Care (including Palliative Home Care), which includes different healthcare providers (e.g., nurses, respiratory therapists, occupational therapists, dietitians, social workers) who come to your home and support you.
  - Supportive Living
  - Facility Living
- Specialized Palliative Care Consult teams, which are made up of doctors and nurses who specialize in palliative care. They can help with managing symptoms, end of life planning, and referrals to a hospice or palliative care units when needed.
- Specialized Geriatrics teams, which do assessments for older adults and make care recommendations. Older adults often have many health problems and can have complex concerns.
- Other medical specialty care teams.

## Continuing Care (home care, supportive living, facility living)

Having a connection with healthcare professionals in the community can make a big difference in your care. We encourage all patients and families to learn about Continuing Care Services (such as home care).

**Plan early**—don't wait until a crisis before you access these services. That way you'll get good care and you'll be where you need to be.

Anyone can make referrals to home care. You can refer yourself or your family member to home care. Depending on where you are, your healthcare professional may recommend palliative home care. To learn more about how home care can support you (both now and in the future), please talk to your healthcare provider or see the information below.

To contact Continuing Care Access:

North Zone: 1-855-371-4122

Edmonton Zone: 780-496-1300

Central Zone: 1-855-371-4122

Calgary Zone: 403-943-1920

South Zone: 1-866-388-6380

## Where will I be cared for if I can't stay at home? Who will look after me?

If you need more help at home, Continuing Care services (like Home Care) can help you and your family.

If it starts to look like staying at home isn't an option for you, talk to your healthcare team about other options. You'll have to contact Continuing Care services to find out about these options, which might include:

- **Supportive Living**, which offers many different supports including meals, housekeeping, and recreation services. People may need Supportive Living because of health or cognitive concerns. Home Care resources are available on site 24/7.
- **Long-Term Care**, which is for people with complex health problems, including difficulties with thinking, or dementia.
- **Hospice/Palliative Care**, which is for people who are closer to the end of their lives. In Alberta, there are many options for this type of care (e.g., your home, at a hospital, a continuing care centre, a hospice). If it's right for you and what you want, you may be referred to a hospice/palliative care unit. Hospice care can usually be arranged within a few days. These units care for people in their last weeks to months of life.

Working closely with your primary care provider, Continuing Care will assess your wishes, needs, and your medical problem(s). After this, they can help you transition to place where you'll be cared for.

Sometimes, people struggle to stay at home for as long as they can. The assessments and planning to go somewhere else can take time—they can't be done in just a day or two. **Plan early**—don't wait until there's a crisis before you access these services. That way you'll get good care and you'll be where you need to be.

## **What if I have emotional, psychological, or spiritual concerns?**

There are resources and people to help you and your family. Some of these providers might be part of your healthcare team, while you might need to be referred to others.

Social workers can help you and your family/support people cope with your health problem and the stress of living with kidney disease. They can help you access other services and resources in your community. If you have Home Care now, you'll likely have access to a social worker or other team members who can help you.

Spiritual Health Practitioners offer spiritual and emotional support to people and their families/support people. They can help you connect or re-connect you with faith-based groups in your community.

Think about this question: Do I have any spiritual concerns that I would like to talk about to my healthcare team?

Your family doctor or NP can also give you information about support services in your community. Go to [www.CKMcare.com](http://www.CKMcare.com) to learn more.

For 24/7 nurse advice and general health information, call Health Link at 811.

## **What if I'm at home and my symptoms get really bad?**

When your kidney function gets very poor, you might start to have more symptoms. We have already talked about many symptoms and how to manage them. You can also talk to your healthcare provider for more information to help you.

Some of your symptoms may be worse than others. It's always a good idea to be prepared and have a plan.

## How can I be prepared?

1. Having an **action plan** may help you manage your symptoms and stay at home if that's what you want. **Please talk to your main healthcare provider and make a plan together.** They may give you prescriptions so you can get medicine fast if you need it.
2. If Home Care is available to you, it is recommended that they know you and what your needs are. They can also help if you need to go somewhere else (e.g., long-term care facility, hospice) because you can't manage at home any longer. If your symptoms become severe, follow your prearranged plan or call 911.
3. It's also important that you've done advance care planning, that you have named an agent, and that you have your completed Goals of Care Designation in your **Green Sleeve** at home.

## Action Plan for Your Symptoms

1. If a symptom is getting worse, take your medicine as prescribed. Keep a record of what you take, when you take it, and if it helps. If you're managing okay, talk to your healthcare provider about your symptom(s) as soon as you can.
2. If a symptom is getting worse quickly or is really bad, call the number that you've been given for your Home Care or Supportive Living team (if you have one). They might be able to offer advice about your medicine. They can access EMS Treat, Assess, and Refer for you if needed or they may tell you to go to the hospital or to call 911.
3. If you can't manage and your symptoms are very bad, call 911 and:
  - tell them you have kidney disease.
  - tell them you have chosen Conservative Kidney Management and you don't want dialysis of any kind.
  - have your green sleeve ready to give to EMS when they arrive.

(See Appendix for sample My Crisis Action Plan)





## **Section 4: Approaching the End of Life**

## **What can I expect in the last days or weeks of life?**

In the last days to weeks of life, you might have some common symptoms like nausea or vomiting, itchiness, restless legs, trouble sleeping, pain, and trouble breathing. Your healthcare team will help you manage your symptoms.

When your kidney function gets very poor, you might start to have other symptoms that can't be managed like loss of appetite, muscle twitching, feeling drowsy, feeling tired, and confusion. You might spend most of your time resting and you might need a lot of help from your family and friends.

### ***The Last Days of Life***

In the last days of life, you may sleep longer, have less energy, or eat and drink less (or maybe nothing at all). Your family and friends might notice that you're less aware. You might be a bit confused and restless at times. This is expected. Healthcare professionals are available to support and help families understand what is happening.

## **What will happen if my family and friends can't care for me at home?**

If you and your family think you need more help than what you can get at home, your healthcare providers will help you make another plan. This might mean going to a place that provides palliative care, like a hospice in your community if possible. If a hospice isn't an option, you might need to go to a hospital for palliative care.

It's likely that your family doctor will be managing your care at this time, so they'll work closely with Home Care and Palliative Care as needed.

## **What should my family and friends know?**

In the last days of life, people may:

- be confused
- be restless
- have trouble breathing or breathe differently
- have an irregular heartbeat
- have changes with how the bowels and bladder work
- have skin changes
- have muscle twitching

These changes are all an expected part of dying. Just being with the person who is dying is the best way to offer comfort and support.



## What do I do when someone dies at home?

Someone has likely died if they:

- stop breathing
- don't have a pulse
- don't respond when you touch them or talk to them

If you think the person has died:

- **Don't** call 911. In Alberta, when a death is expected for medical reasons, you don't need an ambulance or the police.
- Call people for support (e.g., Home Care) if needed. Call the person's family doctor or NP if you need or want to. It's a good idea to talk to the person's doctor or NP **before** the person dies to find out if they want to be called or come to the home at the time of the death.
- Call the funeral home. You may want to keep the body in the home for a while, so tell the funeral home when you want them to come—they're available 24/7. It's a good idea to talk to a funeral home about arrangements **before** the person dies. In Alberta, a healthcare provider doesn't need to come to the home when there's an expected death. The funeral director will call the person's doctor and have them sign the death certificate.





## **Section 5: Grief and Loss**

## Grief and Loss

Grief and loss are part of every stage of your kidney disease. You probably have many worries or questions about what's to come for you and your family members/support people.

Thinking ahead to future losses or death is called anticipatory grief and it's a time to share thoughts and feelings and to start to say goodbye. After a death, the family and support people will face a new kind of grief and will need to look after many practical things too. This can be a confusing and challenging time. Everyone on your healthcare team will support you and your family and friends. Loss, death, grief and mourning are normal and they are also the hardest experiences to go through.

Your healthcare team may be able to give you more resources in your area. There are also more resources you can access by calling 2-1-1 to help find community and social services in a specific part of the province. Additional resources about grief and loss are also available on the CKM website ([www.CKMcare.com](http://www.CKMcare.com)).

### ***Are you working through the Layers of Grief?***

If you are feeling the pain of loss and wondering what is happening to you, you need to know that you are not alone.

Many people experience grief in layers. This section will take you through some of those layers, toward healing.

### **Layers of Grieving**

*Many people experience:*

#### *Feelings*

- guilt
- fear
- anxiety
- anger
- shame
- loneliness
- conflicting feelings
- guilt
- relief
- sadness
- longing
- hopelessness
- helplessness
- numbness and shock

### *Physical Sensations*

- fatigue and lack of energy
- generalized tension
- weight loss or gain
- increased allergic reactions
- tightness in chest/throat
- hollowness/emptiness in the stomach

### *Thoughts*

- confusion and difficulty in concentration
- disbelief or denial
- preoccupation with thoughts about the deceased

### *Spirituality*

- shattered safety
- shaken faith
- questioning why
- spiritual distress

### *Behaviours*

- appetite disturbances
- indecision
- sleep disturbances
- withdrawal
- crying
- restlessness

## **Layers of Self Caring**

*Ask others to allow you the freedom to be you. To experience and feel what is right for you. Remember that we are all different.*

- Let yourself be nurtured
- Be kind and gentle to yourself. Share your grief with others who are supportive and understanding

- Slow down and be patient with yourself
- Rest
- Eat balanced meals
- Risk trying new things
- Express your fears
- Explore what your anger/guilt/regret are all about
- Do what is right for you
- Care for your soul
- Laugh some—laughter is good medicine
- Express yourself: talk—write—find someone who will listen
- Wait before making major decisions
- Recognize you still have strengths and abilities
- Allow yourself to grieve in your time frame, no one else's
- Seek professional help when needed

### **Layers of Healing**

*Healing will happen in its own time with work and support.*

Accept the reality of the loss that may include:

- shock, disbelief, denial
- accepting the facts surrounding the loss
- the knowledge that death is irreversible

Experience the pain of grief accompanied by:

- constant thoughts of the person who died
- yearning for the presence of the person who died

Adjust to an environment in which the person who died is missing:

- being aware of all the roles their person who died played in his/her life
- learning to live without that person
- coming to terms with the loss of the future you planned

Say yes to life again:

- experience energy in yourself and with others
- begin to trust and allow closeness
- imagine a future without the person who died
- begin to plan, gradually, for your new future

**Grief:**

- is a process
- is real and normal
- is unique and personal
- is neither right nor wrong
- needs expression and time
- is life changing
- needs to be lived through
- can pile up
- can be overwhelming
- can shake your faith
- is like a cut, it goes through stages of healing and may leave a scar
- is a walk through pain that can lead to healing and a new day dawning in your life
- Can become complicated by:
  - sudden death
  - trauma
  - murder or suicide
  - multiple losses
  - involvement with the media or justice system

*Adapted from AHS "Are you Working Through the Layers of Grief?" January, 2010*







## **Section 6: Appendix**

## Useful Contacts

For information regarding individual patient healthcare concerns, please direct questions to the patient's healthcare provider or team.

### To contact AHS Continuing Care (Home Care, Supportive Living, Facility Living)

- North Zone: 1-855-371-4122
- Edmonton Zone: 780-496-1300
- Central Zone: 1-855-371-4122
- Calgary Zone: 403-943-1920
- South Zone: 1-866-388-6380

To self-refer to the **Calgary Grief Support** program call: 955-8016

To find community and social services in a specific part of the province, call: 2-1-1

To contact **Health Link**, call: 8-1-1

To request **peer support** for patients or family members through the Kidney Foundation, call 1-866-390-PEER (7337)

**Conservative Kidney Management website:**

[www.CKMcare.com](http://www.CKMcare.com)



# Patient Pathway: Choosing Conservative Kidney Management (CKM)

**My Health:** Stable  
**My Kidney Function:** 15-10  
**My Life expectancy:** Years

**Deteriorating**  
10-5  
Years to months

**Rapidly declining**  
5-0  
Last months

## Choosing CKM

Consider using the Patient Decision Aid tool to determine if CKM is the right choice for you.

The aim is to balance quality of life with protecting your kidney function. If a test, medication, or diet restriction doesn't make you feel better or is difficult, your team might suggest stopping it.

Over time, the focus will shift to your comfort and quality of life. Your lab work and medications may stop, unless there is a clear benefit to you. Your team may confirm your choice for CKM at this point.

Your care is focused on quality of life and symptom management now. You probably won't have any lab work. The only medications you take will be ones that help you feel better.

## Conservative Kidney Management

Many symptoms can be managed without medication. Together with you, your care team will create a plan to address your symptoms. Symptoms may include nausea/vomiting, itch, restless legs, tiredness, anxiety/depression, trouble sleeping, and shortness of breath. You might also have pain from other health conditions.

You might notice confusion, drowsiness, muscle twitching, and have a poor appetite. This is normal and we will do our best to keep you comfortable.

## Your Symptoms

Start Advance Care Planning (ACP). Remember to keep your Green Sleeve on your fridge and bring it to your appointments or hospital.

Continue ACP. Ensure your Personal Directive and Goals of Care Designation are up to date.

If you plan to remain at home or hospice at the end of life, your Goals of Care Designation will be C1 or C2.

## Advance Care Planning (ACP)

Your family doctor or nephrologist will guide your kidney care. Palliative Care can be involved at any time to help with symptom management and planning.

At some point, you might decide to come less often to the kidney clinic. You might still connect by Telehealth or phone, or your family doctor may manage your kidney care.

Your family doctor may now guide your care. Palliative Care may also be involved. Your kidney team can still support you as needed.

## Care Teams

You can likely care for most of your own needs with occasional help. If you are at home, learn about Home Care early on. Emotional and spiritual support are also available.

You may spend more than half of your time in bed or lying down. Home Care can help you remain at home or arrange other options. Emotional and spiritual support remains available.

## Crisis Plan

Talk to your care providers about what matters to you. Together, you will come up with a Crisis Plan for your symptoms.

## End of Life Plan

You can ask for information about what to expect at the end of life. Your family may also need extra support to prepare for your death and afterward.

## Grief & Loss

Grief Support is available for your loved ones.



Edmonton Symptom Assessment System Revised: Renal (ESAS-r: Renal)

Please circle the number that best describes how you feel NOW:

Table with 12 rows of symptom assessment items (e.g., No Pain, No Tiredness, No Drowsiness, No Nausea, No Lack of Appetite, No Shortness of Breath, No Depression, No Anxiety, Best Wellbeing, No Itching, No Problem Sleeping, No Restless Leg) and a scale from 0 to 10.

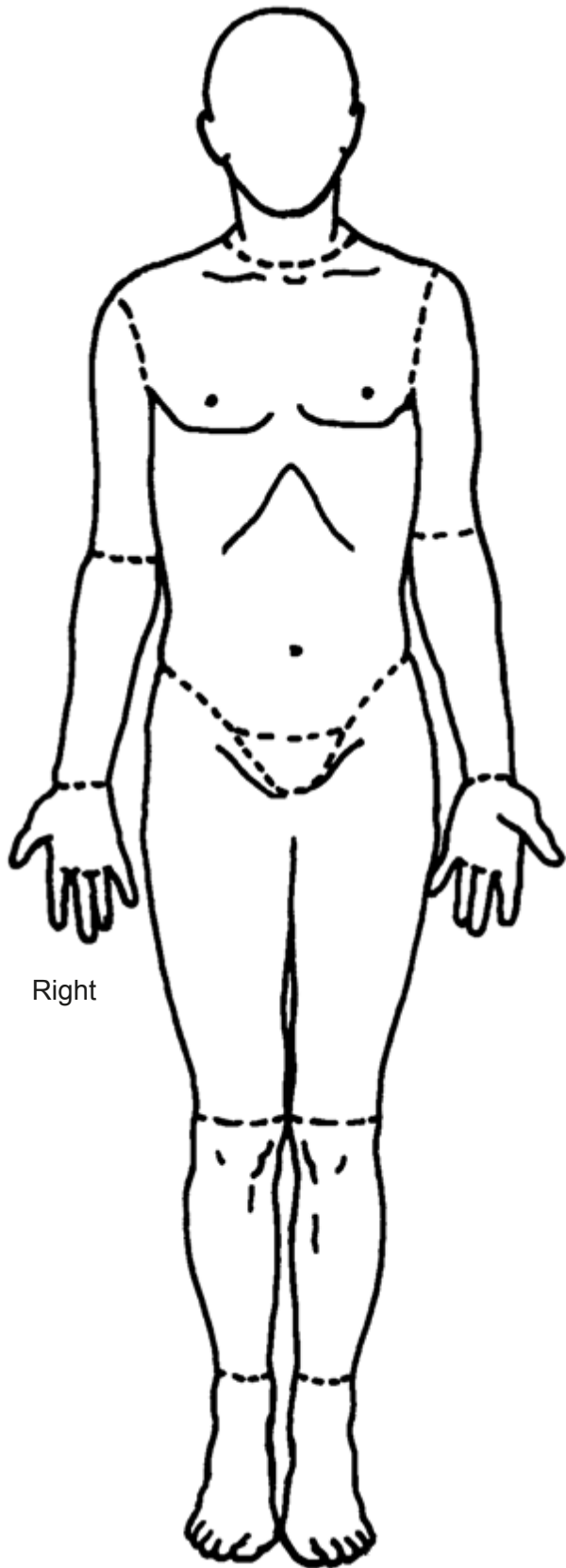
Patient's Name \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

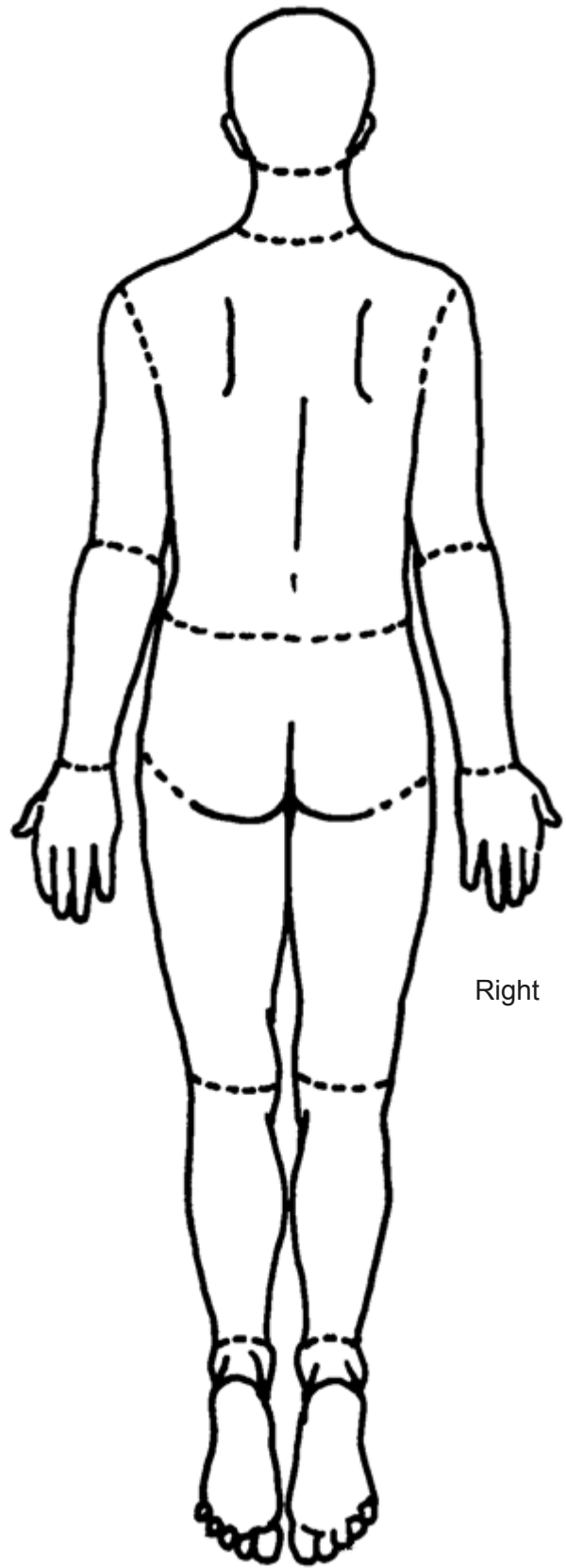
Completed by (check one):

- Completed by (check one):
[ ] Patient
[ ] Family caregiver
[ ] Health care professional caregiver
[ ] Caregiver-assisted

Please mark on these pictures where it is that you hurt:



Right



Right

# IPOS-Renal Patient Version



www.pos-pal.org

Patient name : .....

Date (dd/mm/yyyy) : .....

Patient number : ..... (for staff use)

**Q1. What have been your main problems or concerns over the past week??**

1. ....
2. ....
3. ....

**Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?**

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
<b>Pain</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Shortness of breath</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Weakness or lack of energy</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Nausea (feeling like you are going to be sick)</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Vomiting (being sick)</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Poor appetite</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Constipation</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Sore or dry mouth</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Drowsiness</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Poor mobility</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Itching</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Difficulty Sleeping</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Restless legs or difficulty keeping legs still</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Changes in skin</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<b>Diarrhoea</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

**Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?**

1. \_\_\_\_\_ 0  1  2  3  4
2. \_\_\_\_\_ 0  1  2  3  4
3. \_\_\_\_\_ 0  1  2  3  4

**Over the past week:**

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
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Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
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	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
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Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
---	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	None at all	Up to half a day wasted	More than half a day wasted
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>

	On my own	With help from a friend or relative	With help from a member of staff
Q11. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse**

## Symptom Diary

If you wish, you can use the following pages for keeping a record of your symptoms. These are just examples. This information can be helpful when you talk to your healthcare team. You could also use these examples for other symptoms like tiredness, anxiety, and depression.

Daily Pain Diary									
Date:									
Time:									
Pain Rating (0–10):									
How does my pain feel? ( <i>ache, throbbing, burning, shooting, tingling</i> )									
How long does my pain last? ( <i>minutes, hours, constant</i> )									
What time of day was my pain: the best?									
the worst?									
What made my pain: better today?									
worse today?									
Medicine and dose:									
Medicine side effects:									
This was my pain rating one hour after the medicine:									

0

No pain

1

2

3

4

5

Moderate pain

6

7

8

9

10

Worst possible pain



Daily Nausea Diary									
Date:									
Time:									
Nausea Rating (0–10):									
What time of day was my nausea: the best?									
the worst?									
What made my nausea: better today?									
worse today?									
Medicine and dose:									
Medicine side effects:									
This was my nausea rating one hour after the medicine:									

0 No nausea      1      2      3      4      5 Moderate nausea      6      7      8      9      10 Worst possible nausea

Daily Itching (Pruritus) Diary									
Date:									
Time:									
Itching Rating (0–10):									
What time of day was my itching: the best?									
the worst?									
What made my itching: better today?									
worse today?									
Medicine and dose:									
Medicine side effects:									
This was my itching rating one hour after the medicine:									

0 No itching      1      2      3      4      5 Moderate itching      6      7      8      9      10 Worst possible itching

Daily Restless Legs Diary									
Date:									
Time:									
Restless Legs Rating (0–10):									
What time of day were my restless legs: the best?									
the worst?									
What made my restless legs: better today?									
worse today?									
Medicine and dose:									
Medicine side effects:									
This was my restless legs rating one hour after the medicine:									

0 No restless legs      1      2      3      4      5 Moderate restless legs      6      7      8      9      10 Worst possible restless legs

Daily Breathing Diary									
Date:									
Time:									
Breathing Rating (0–10):									
What time of day was my breathing: the best?									
the worst?									
What made my breathing: better today?									
worse today?									
Medicine and dose:									
Medicine side effects:									
This was my breathing rating one hour after the medicine:									

0 No shortness of breath

1

2

3

4

5 Moderate shortness of breath

6

7

8

9

10 Worst possible shortness of breath



Patient label placed here (if applicable) or if labels are not used, minimum information below is required.

Name <i>(last first)</i>
Birthdate <i>(yyyy-Mon-dd)</i>
Gender
PHN

## My Crisis Action Plan

### What is a crisis action plan?

A crisis action plan is used to plan for and be prepared for a decline in your kidney function. This plan will help you: know who to call (**SUPPORT**), which medication to take (**SYMPTOM**) and what to do in an **EMERGENCY**, as your kidney function worsens.

<b>SUPPORT</b>	<b>SYMPTOMS</b>	<b>EMERGENCY</b>
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### SUPPORT:

My Name: \_\_\_\_\_

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

Phone Number: \_\_\_\_\_

My Home Care Case Manager: \_\_\_\_\_

Phone Number: \_\_\_\_\_

My Chronic Kidney Disease Clinic: \_\_\_\_\_

Phone Number: \_\_\_\_\_

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

Phone Number: \_\_\_\_\_

If you are living at home and require daily assistance (with showering/dressing/toileting/medication), we strongly encourage you to have **homecare** involved. The home care relationship will be very important if you start to have trouble at home and need care quickly. This could include helping you go somewhere else to live, such as a long-term care facility or hospice, if you can no longer manage at home. You can refer yourself or your loved one to homecare – you can learn more at [www.ckmcare.com](http://www.ckmcare.com) under "Resources".

It is also important that you have engaged in **advance care planning**, and that you have a personal directive and a signed Goals of Care designation form in your **Green Sleeve** at home.

### SYMPTOMS:

#### What can I expect?

When your kidney function gets very poor, there are some common symptoms that you might experience. These could include **nausea/vomiting, itchiness, sleep difficulties, restless legs, and trouble breathing**. You might have **pain** from other conditions as well. Your care provider can give you more information on each of these symptoms and can help you manage them.

You might start to experience other symptoms that we are not able to reverse. These include loss of appetite, muscle twitching, drowsiness, tiredness, and confusion. Some of these symptoms may be more distressing than others.

#### How can I be prepared?

In addition to caring for your symptoms using things such as: heat packs, music therapy, relaxation techniques etc., you can take **prescribed medication** to help you relieve your distressing symptoms. You and your health care provider should discuss which kind, how much and how often you should take your medication, to address each symptom.

## My Crisis Action Plan

Use this table to organize your medications for when you are experiencing:

**Pain Medication:** \_\_\_\_\_

Regular Dose:

Breakthrough Dose:

**Shortness of Breath Medication:** \_\_\_\_\_

Regular Dose:

Breakthrough Dose:

**Nausea/Vomiting Medication:** \_\_\_\_\_

Regular Dose:

Breakthrough Dose:

**Restlessness/Confusion Medication:** \_\_\_\_\_

Regular Dose:

Breakthrough Dose:

**Any Other Symptom(s)** (Ie. Hyperkalemia) \_\_\_\_\_ **Medication:** \_\_\_\_\_

Regular Dose:

Breakthrough Dose:

- ❖ Keep a record of what you take, when you took it, and what your response to the medicine was.
- ❖ See or talk to one of your health care providers (as noted under **SUPPORT**) on a **regular basis**.

### EMERGENCY:

If a symptom is getting worse quickly or is very bad, **call a member of your support team** (as you filled in under **SUPPORT**). Try to call your family physician or home care case manager first. They might be able to give you guidance about your medicine and how to address your emergency.

If needed, a member of your **SUPPORT** team can access **EMS (Emergency Medical Service) Palliative & End of Life Care Assess, Treat and Refer on your behalf**. While working collaboratively with your **SUPPORT** team, EMS professionals will attempt to treat your palliative symptoms (such as shortness of breath or pain) in your home.

Depending on the situation, EMS personnel may need to take you to go to the hospital for further testing or treatment. Make sure to take your green sleeve with you to the hospital.

**If you are unable to reach a member of your SUPPORT team, and your symptoms are severe, phone 911.**

- Tell the EMS personnel **in your home** that:
  - You have end stage kidney disease
  - You have **CHOSEN Conservative Kidney Management** – you have chosen **not to have dialysis** of any kind.
  - You are receiving **palliative care**.
- Have your green sleeve ready to give to EMS, including your **crisis action plan** and the **Health Care Provider (HCP) Crisis Action Plan**.

# Health Care Professional (HCP) Crisis Action Plan for Patients who have chosen Conservative Kidney Management

Patient label placed here (if applicable) or if labels are not used, minimum information below is required.

Name (last first)
Birthdate (yyyy-Mon-dd)
Gender
PHN

**Patients:** In the event that you or your loved one needs to call 911 or go to an emergency department, please give the health care professionals caring for you this sheet. It will inform how they should care for your symptoms, keeping in mind that you have chosen **Conservative Kidney Management**. We **strongly recommend** you keep this sheet in your **Green Sleeve**.

## HCPs: refer to the online clinical pathway to access *Symptom Guidelines & Algorithms* at [www.ckmcare.com](http://www.ckmcare.com)

Here are current CKM guidelines and rationale commonly used for crisis management for patients with End Stage Kidney Disease.

Symptom:	Suggested Pharmacological Treatment:	Rationale for Client's with End Stage Kidney Disease:
<b>PAIN</b>	<ol style="list-style-type: none"> <li>1. Fentanyl 12.5 mcg SC/SL/IN</li> <li>2. Hydromorphone (Dilaudid) 0.2 mg SC (0.5 mg PO)</li> </ol>	<p>Fentanyl is fast-acting, has a short half-life, and is a preferred opioid for kidney failure.</p> <p><b>Note that morphine is not recommended for patients with end stage kidney disease.</b> Even if a patient is actively dying, metabolites can accumulate and contribute to toxicity.</p>
<b>SHORTNESS OF BREATH</b>	<ol style="list-style-type: none"> <li>1. Furosemide (Lasix) 40 mg IV</li> <li>2. Fentanyl 12.5 mcg SC/SL/IN</li> <li>3. Hydromorphone (Dilaudid) 0.2 mg SC (0.5 mg PO)</li> <li>4. Lorazepam (Ativan) 1 mg PO</li> </ol>	<p><b>The most common cause of breathlessness in this patient population is pulmonary edema.</b> If the patient is still short of breath after furosemide treatment, consider opioids.</p> <p><b>Opioids are the most effective drugs for the treatment of breathlessness in end-stage kidney disease.</b> Due to its fast action, <b>fentanyl</b> works well for breathlessness. <b>It is a preferred opioid for end stage kidney disease.</b></p>
<b>NAUSEA/ VOMITING</b>	<ol style="list-style-type: none"> <li>1. Ondansetron (Zofran) 4 mg PO/SC</li> <li>2. Metoclopramide (Maxeran) 2.5 mg PO/SC</li> <li>3. Haloperidol (Haldol) 0.5–1 mg SC</li> </ol>	<p>If Zofran is ineffective, consider Maxeran 2.5 mg PO/SC. If nausea persists, consider Haldol 0.5–1 mg PO/SC. Do not give both haloperidol and maxeran: both are dopamine antagonists and can accumulate in end stage kidney disease. <b>Doses are typically reduced by 50%.</b> Haldol is being used off-label for nausea.</p>
<b>RESTLESSNESS/ CONFUSION</b>	<ol style="list-style-type: none"> <li>1. Haloperidol (Haldol) 0.5–1mg SC</li> <li>2. Midazolam (Versed) 1–5 mg SC</li> </ol>	<p>Haldol can accumulate in End Stage Kidney Disease. The dose is typically reduced by 50%. If agitation or restlessness persists, consider midazolam 1–5 mg SC.</p>

Patient: _____	Phone Number: _____
Family Physician: _____	Phone Number: _____
Home Care Case Manager: _____	Phone Number: _____
Chronic Kidney Disease Clinic: _____	Phone Number: _____
Pharmacy: _____	Phone Number: _____









# CONSERVATIVE

KIDNEY MANAGEMENT

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