# ACTIVE MEDICAL MANAGEMENT WITHOUT DIALYSIS PATHWAY

These Active Medical Management without Dialysis tools were created as part of the Pathways Project
https://nursing.gwu.edu/pathways-project
funded by the Gordon & Betty Moore Foundation.

The Pathways Project is an initiative of the Coalition for Supportive Care of Kidney Patients, which is housed within George Washington University School of Nursing

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Thank you to the programs and clinicians who gave permission to have their existing tools adapted and included in this toolkit with special thanks to Sara N. Davison, MD on behalf of the Kidney Supportive Care Research Group and Alberta Health Services. Conservative Kidney Management Crisis Action Plan. www.CKMcare.com. 2019.

Coalition for Supportive Care of Kidney Patients

PATHWAYS Project

# Active Medical Management without Dialysis Pathway

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## SECTION B: RESOURCES FOR PATIENTS

Coalition for Supportive Care of Kidney Patients

# Essentials of Active Medical Management without Dialysis

## Care Way for Medical Management without Dialysis



| Health | Stable | Moderate decline | Steep decline | End of life |
|---|---|---|---|---|
| Kidney function | GFR ~20-15 | GFR ~14-5 | GFR ~<5 | GFR ~0 |
| Co-morbidities/frailty/ function | *Able to care for personal needs* | *Requires assistance with some personal needs* | *Dependent on others for needs* | *Hospice or hospital care* |
| Life expectancy | Years | Years to months | Months-days | Weeks-days |




PLAN | MANAGE | INTENSIVE SUPPORT | END OF LIFE/ BEREAVEMENT

# Care Way for Medical Management Without Dialysis (MMWD)

**Plan**

- Shared decision-making to choose treatment mode
- Patient education material describing MMWD objectively
- Engage families
- Create alert in chart for MMWD

**Manage**

- CKD care
- Symptom assessment & management
- Advance care planning
- POLST/MOLST - specifies no dialysis
- Case management with regular check in calls monthly
- Introduce contingency action plan, including who to contact
- Palliative care (primary or consult) for complex symptoms
- Introduce hospice

**Intensive Support**

- Educate patient & family on watching for escalating uremic symptoms
- "Safety net" to catch patient before ED/hospitalization
- Triggers for update of advance care plan (e.g. hospitalization)
- Implement contingency action plan when needed
- Hospice evaluation and admission as appropriate

**End-of-Life/ Bereavement**

- Hospice admission
- Bereavement contact. refer to grief resources

Shaded area = New service needed for comprehensive Medical Management CareWay

If patient changes mind and wants to try dialytic treatment, consider:
- Time limited trial of dialysis (HD or PD)
- Palliative dialysis

EXAMPLE: The Active Medical Management without Dialysis "Care Way" for the DC VA

*Adapt this to your program and local resources*

| Stage of Care | Team Action | Resources |
|---|---|---|
| Establish team processes | | |
| Champions and team | • Identify change "champion"<br>• Identify team members<br>• Include social worker, psychologist and chaplain, if possible | |
| Regular team process | Establish regular meeting where Active Medical Management patient cases are discussed | |
| Training/education for team | • Provide resources, orientation to team members<br>• Provide communication skills training as needed | |
| Identify patients | | |
| Identify patients likely to benefit from considering option | Systematically review CKD patients and identify ones likely to do poorly on dialysis | • Surprise Question<br>• Pathways Prognostic markers list<br>• Prognostic calculator for CKD: https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients<br>• Age/functional screen – frailty, cognitive impairment |
| Patient deciding on treatment mode | Offer prognostic information to extent patient wants it | • Prognostic calculator (for clinician) https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients<br>• Pathways Ask-Tell-Ask card approach |
| | • Use patient education material that describes Active Medical Management Without Dialysis in objective way<br>• Address emotional aspects of decision-making | • Health professionals' guide to My Kidneys, My Choice decision aid: http://kidney.org.au/cms_uploads/docs/my-kidney_my-choice_health-professionals.pdf<br>• Pathways patient brochure: Making a Choice to Live Well Without Dialysis<br>• My Kidneys, My Choice – booklet decision aid for patient |

| | | |
|---|---|---|
| | • Incorporate patient's spiritual and religious views/beliefs in decision-making | https://www.kidneys.co.nz/resources/file/mykidneymychoice_digital.pdf<br>• Best Case/Worst Case Decision Aid<br>• Alberta CKM Care- patient decision aid: https://www.ckmcare.com/CKMPathway/PathwayIntroduction<br>• Yorkshire Dialysis Decision Aid: http://www.yodda.leeds.ac.uk/Survey/Outcomes?page=8 |
| | | • For patients who are ambivalent or where there is family conflict, consult Palliative Care for help with clarifying goals |
| Patient has chosen active medical management | | |
| Patient chooses Active Medical Management (expected to be 15%-20% of geriatric patients) | Support choice.<br>Describe the "Care Way" | • Pathways Patient Action Plan<br>• Future: develop additional patient educational handout describing steps |
| | Document active medical management care plan in LST section of chart | (need to develop example of language for LST on patients who do not want dialysis)<br>• Completion of POLST/MOLST form |
| Continue to support optimal kidney function | Optimal renal care to support residual kidney function, including regular lab monitoring | |
| | Renal management plan – visit nephrologist every 1-2 months (stage 5 CKD), when GFR <10, visit monthly. Provide anticipatory guidance to help patient and family know and plan for next phase. | |
| | Consider regular telephone support or case management | |
| | Symptom management -- use comprehensive symptom screen such as IPOS renal at least once per month. | See symptom guidelines at Albert CKMcare https://www.ckmcare.com/InformationRows/PracSymptoms |

| | | |
|---|---|---|
| | Symptoms may be co-managed with PCP. | - Consult palliative care for uncontrolled symptoms |
| Advance Care Planning | Conduct advance care planning and document<br>- document selected decision-maker<br>- if needed, assist patient to communicate with decision-maker<br>- enter LST note<br>- Revisit patient goals periodically, especially after change in health status or hospitalizaitons<br>- By time GFR<10, put POLST/DNR in place according to patient wishes | Consult palliative care for help with complex advance care planning (e.g. patient unable to identify decision-maker, or conflict in family)<br>- consult palliative care if non-renal aspects of ACP are complex |
| Comprehensive/whole person care | Especially for geriatric or frail patients, establish a comprehensive plan that addresses entire situation | - See additional list of tools/resources for whole person and integrative care<br>- Geriatric or PC consult to conduct comprehensive geriatric assessment, establish plan for additional services, especially in home services and caregiver support |
| Emergency plan/transition plan | Develop plan with patient about handling escalating symptoms.<br>Document in LST patient goals (such as no dialysis, remaining home)<br>Educate patient/caregiver on what signs to look for that indicate increasing problems, who to call. | Pathways Healthcare Provider Action Plan |
| Escalating symptoms | | |
| Escalating symptoms | Monitor closely (weekly?) for changes that suggest EOL approaching | - Home/transition service to monitor via weekly telephone calls |
| | Hospice educational visit to familiarize patient with hospice options | |
| End of life | | |
| EOL | Hospice admission<br>Or Palliative team support | |
| Bereavement | | |
| Bereavement | Send bereavement card or letter. | |

| | | |
|---|---|---|
| | Phone contact with family after death.<br>For complex grief, local hospice may have additional services. | |

**Shared Decision-Making Consent Form for End-Stage Kidney Disease Treatment Options***

**Patient consent** (*To be completed by patient)*

Dr. _____ and I have talked about my kidney health and the ways it might be treated, and we have decided to proceed with:

☐ **KIDNEY TRANSPLANT**

☐ **PERITONEAL DIALYSIS**

☐ **HOME HEMODIALYSIS**

☐ **IN-CENTER HEMODIALYSIS**

☐ **ACTIVE MEDICAL MANAGEMENT WITHOUT DIALYSIS**

☐ **A TIME-LIMITED TRIAL OF DIALYSIS**

The doctor has explained the following:

☐ The role and process of each treatment choice.

☐ Benefits and risks of the treatment choices, including the likely time course of my kidney health with each of the options.

☐ The expected effect on my life, and the support I may need now or in the future from my family and caregivers.

☐ I have had all my questions answered to my satisfaction and I have enough information to make this decision.

☐ I am making this decision freely, and understand I can change my mind and withdraw my consent at any time.

_____ (signature of patient) _____ (date)

_____ (print name of patient) _____ (date)

**Clinician Statement of Provision of Information to Patient** (*To be completed by nephrologist/APP)*

I, Dr. _____ have discussed with _____(patient name) treatment options for end-stage kidney disease including kidney transplant, peritoneal dialysis, home hemodialysis, in-center hemodialysis, a time-limited trial of dialysis and active medical management without dialysis.

☐ At this time, _____ has decision-making capacity to give informed consent.

☐ I have educated regarding all treatment options, explained risks and benefits, checked for understanding, and provided opportunities to ask questions.

☐ I have explained potential complications including vascular access or catheter problems, infection, blood pressure changes, fluid overload, fatigue after dialysis, heart attack, stroke or blood clots, hospital care, and death.

☐ I have explained the options using the Best Case/Worst Case Decision Aid.

☐ On this date, I have provided a Patient Information handout on treatment options.

☐ I am satisfied that _____ is making a voluntary informed values-based decision.

_____ (signature of nephrologist) _____ (date)

_____ (signature of patient) _____ (date)

*Adapted from K. Li and M. Brown. Consenting for Dialysis or Its Alternative: Systematic Process Is Needed. *CJASN* 2020.

**PATIENT INFORMATION AND DECISION AIDS**

Patient decision aid tool from Alberta, Canada Health Services https://www.ckmcare.com/CKMPathway/PathwayIntroduction

Information for Patients about Advanced Kidney Disease: Dialysis and Non-Dialysis Treatments from Renal and Hypertension Service, St. George and Sutherland Hospitals, New South Wales, Australia https://stgrenal.org.au/patients

**How the Best Case/Worst Case tool works:** The clinician verbally describes the "best case," "worst case," and "most likely" outcomes for each treatment option—incorporating rich narrative from clinical experience and patient-specific relevant outcomes—while drawing a graphic aid of those options (Figure 2). Vertical bars represent treatment options; their length shows the range of outcomes and the magnitude of the difference between the "best case" (star), the "worst case" (box) and a "most likely case" (oval). The clinician also writes short notes about each option on the diagram, which helps the patient recall details of the conversation later. The narrative description and graphic aid help the patient formulate and express preferences. From this exchange, the clinician can then provide a treatment recommendation that is grounded in the relevant clinical context and reflects the patient's values. A copy of the graphic aid is stored in the patient's chart. Patients also retain the graphic aid to discuss options with family and to support future conversations with their nephrologist and other clinicians.

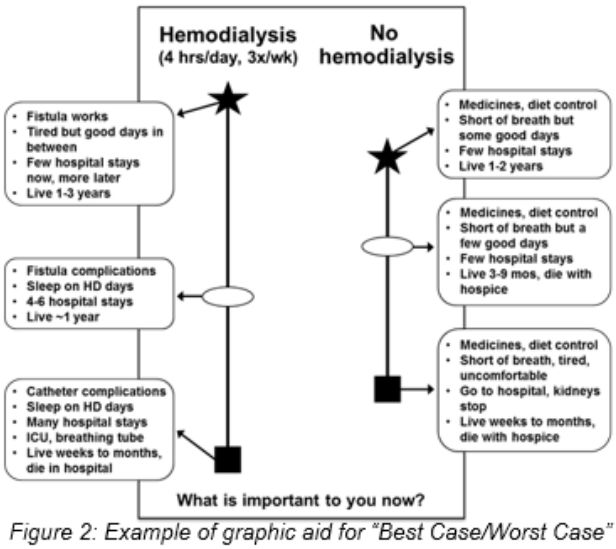


*Figure 2: Example of graphic aid for "Best Case/Worst Case"*

Letter to primary care clinician.

Remove and insert your logo or print on your letterhead.

Date

Dear Doctor _____,

I wish to inform you that our mutual patient, _____, has advanced chronic kidney disease and **has chosen not to have dialysis.** This decision has been made after lengthy discussion with the patient, family, and health staff team about the patient's values, preferences, and goals. S/He is now being followed by the **Active Medical Management without Dialysis Program** at the Chronic Kidney Disease (CKD) Clinic at [clinic name].

The rate of progression of kidney disease is variable and his/her kidney function may remain stable for some time. We will continue to manage his/her kidney disease with a focus on quality of life. Issues that we will continue to address include management of anemia, fatigue, pruritus, other symptoms, blood pressure, volume status, bone mineral metabolism, and electrolyte abnormalities. Uremia is often painless, but some individuals may develop pain from other comorbidities that requires treatment. If you wish to treat kidney disease-related symptoms, please let us know. Otherwise we will manage symptoms as part of the patient's CKD care.

As kidney function declines and symptom burden worsens, we will need to address end-of-life care. Our multidisciplinary team will work towards optimizing home support services for our patient and his/her family. We will collaborate with local palliative care teams and/or hospices and will refer our patient to them when appropriate. We will also help our patient and his/her family in advance care planning and preparing for end of life.

We hope to work collaboratively with you to support our patient's needs and wishes. **Should you have any questions or concerns, please contact the Chronic Kidney Disease Clinic at [phone and email contact] or the on-call nephrologist (after hours) through [contact instructions]**

Thank you for allowing us to participate in your patient's care.

Sincerely,

[name of nephrologist]

Nephrologist
Active Medical Management without Dialysis Program
Chronic Kidney Disease Clinic, [institution name]
Cc: all specialists involved

Version: 2/5/20

(From Chandra Thomas & Ruth de Boer RN, BAH, C Neph (c)
Nurse Clinician Advance Care Planning
Southern Alberta Renal Program

Patient Name:

## Patient Contact Checklist – Active Medical Management Without Dialysis Team's Guide

**Symptom assessment and control**

- Has there been a detailed assessment of symptoms (**ESAS** or POS)?
- Is there a management plan in place?
- Is there appropriate access to therapies?

**Medication/investigation rationalization**

- Are the current medications in line with the patient's identified goals/disease trajectory?
- Is the current investigation plan in line with the patient's identified goals/disease trajectory?
- Has the bloodwork been rationalized?

**Patient choice**

- Is the patient still happy with the decision to forgo dialysis?
- What is the preferred place of care as the illness progresses?
- Has ACP taken place?

**Resuscitation status**

- Have goals of care been discussed with the patient?
- Are GOC entered in Paris?
- Is the appropriate goals of care form signed?
- Is the **green sleeve** in the home and brought with the patient to clinic?
- Has the GOC form been faxed to Palliative Home Care?

**Family/carer information/education**

- Has the patient been asked about sharing information with family?
- Has family discussion taken place where appropriate?
- Have plans for crisis situations been discussed and understood by the carer/family
- Have the carer/family been provided with the contact information for the relevant services?

**Spiritual need**

- Have the spiritual needs of the patient been discussed and addressed?

**Death preparation**

- Does the patient have a will?
- Have opportunities for leaving a legacy been discussed/facilitated?
- Have funeral arrangements been discussed?
- Has the patient decided on a preferred place of care?
- Has the patient/family toured hospice?

**Crisis planning**

- Have possible events been identified?
- Has anticipatory education been provided?
- Are management plans in place?
- Are medications available?
- Has the Palliative Blue Cross form been sent?

- Have the “NOTES” section of Paris been updated?
- Are the GOC form & **green sleeve** in the patient’s house?
- Are contact numbers about who to call available?
    - CKD Nurse Clinician
    - GP _____
    - Nephrologist _____
    - Rapid Response Home Care Team # 403-943-1600
    - Palliative MD on call

**Bereavement checklist**

- Has a Quality of Dying APGAR been filled out by the team?
- Have all staff/teams involved been given the opportunity to sign a condolence card?
- Has a condolence card been sent to the family?
- Has spiritual care contacted the family after the death?
- Has the family been given an opportunity to meet with the palliative care team to debrief on their loved ones death/end of life experience?
- Has a post death questionnaire been mailed to the family several months after the death?
- Has a post death questionnaire been received back from the family?
- Have any issues brought up in the post death questionnaire been reviewed and discussed with the family?
- Have staff and family been given the opportunity to attend a memorial service hosted by SARP?

**Template for outpatient CKD consultation and management for patient who prefers not to start dialysis**

**Primary Care MD:** @PCP@

**REASON FOR CONSULT:** initial consultation for CKD.

**@PMH@**

**HOPI:**
@NAME@ is a @AGE@ @CAPSEX@ with history as noted above who comes in for ****

**What is your understanding about your kidney disease?**
**How serious is it?**
**What matters the most to you in treatment of your kidney disease?**
**What do you wish to avoid?**
**What are you hoping for?**
**What helps you cope?**
**What bothers you the most about your kidney disease?**
**Who would you want to make medical decisions for you if you were too sick to make them yourself?**

**Palliative Care Performance Scale (PPS) :**

**Spiritual history:**

**@SOCHX@**

**@FAMHX@**

**@PSH@**

**Review of Systems:**

**10 point ROS obtained.**

**Positive for:**
**Negative for:**

**Allergies:** @ALLERGY@
@CMED@

**Physical Examination:**
@V@
General: Alert, pleasant
HEENT: No obvious deformity, normocephalic
Chest: CTABL, normal excursion
Abd: Soft, NT
CVS: S1 + S2 , could not hear any murmur
Legs: no edema, no rash

Skin: no new rash
Neuro: Moving all limbs, alert
Psych: Calm and happy at the time of my exam.

**Lab Results:**

| |
|---|
| @BRIEFLABTABLE(Na,K,Cl,CO2,UN,creat,GFRC,GFRB,glu,HA1c,ca,PO4,PTH,VID25,UTPR,UCRR,malbr,malbm,macr)@ |
| @BRIEFLABTABLE(WBC,HGB,HCT,PLT,FE,IBC,FESAT,FER)@ |

**Assessment/ Plan:**
@NAME@ is a @AGE@ @CAPSEX@ who comes for an evaluation of ***.

**(1) CKD G **A **:** Most likely as a result of

**(2) HTN:** BP is controlled/uncontrolled. Target BP per JNC8 Guidelines is <140/90 mmHg.
- Continue current meds.
- Low salt diet.

**(3) Proteinuria:** ***. No changes.

**(4) Anemia:** Hb at goal/low. No need for EPO. Iron stores adequate/inadequate.

**(5) Mineral Bone Disease:** Phos, vitamin D and PTH at goal. Continue to monitor these indices.

**(6) Potassium Balance:** K acceptable/elevated. Low K diet. Low K diet sheet provided.

**(7) Acid/base status:** HCO3 acceptable/low. No changes./Will start NaHCO3.

**(8) Goals of Renal Care:**
**Life Goals/Preferences**
**MOLST**
**HCP**

Return to clinic in ***months/year with labs every ***months/year.

Thank you very much for this consult. Do not hesitate to call us for questions.

Adapted with permission of Fahad Saeed, MBBS, FASN
Department of Medicine
Divisions of Nephrology and Palliative Care
University of Rochester School of Medicine

Worksheet for Testing Changes to Implement Active Medical Management Without Dialysis- Example

Date: Facility Name:

AIM: (Overall Goal you would like to reach) Establish/ expand MMWD program to include needed provider and patient-family communication, education, preparation and condition monitoring to facilitate proactive intervention whenever possible to avoid unwanted care.

1. 75% of SI CKD Stage 4-5 patients that have chosen MMWD will be educated about and understand a Contingency plan to avoid unwanted care 2. 100% of providers caring for CKD patients in the organization will be educated about the program and understand their role in respecting and working to meet patients stated goals of care.

**P L A N**

| **Describe your first (or next) test of change** | **Who** | **When** | **Where (if applicable)** |
|---|---|---|---|
| 1. Present and receive any needed approvals of the program/ documents.<br>2. Educate involved CKD providers.<br>3. Implement contingency contact system<br>4. Implement patient condition monitoring system<br>5. Choose 2 patients for testing the packet/ system and educate/ implement | | | |

| **List the tasks needed to set up this test of change** | **Who** | **When** | **Where (if applicable)** |
|---|---|---|---|
| 1. Present packet/ plan/ documents for approvals to XXXXX<br>a. Apply logo<br>b. Print<br>c. Obtain packets<br>d. Assemble packets | | | |
| 2. Identify and educate CKD providers involved in test<br>a. Prepare list<br>b. Schedule education session<br>c. Conduct session<br>c. Assess engagement/ commitment | | | |
| 3. Implement contact system<br>a. Identify persons/ numbers for calls following contingency plan<br>c. test system with staff | | | |

| | | | |
|---|---|---|---|
| 4. Implement condition monitoring system<br>a. Determine frequency of contact<br>b. Assign staff<br>c. Determine documentation/ EHR | | | |
| 5. Choose 2 patients for testing the packet/ system and educate/ implement<br>a. schedule visit<br>b. Educate on packet<br>c. Establish condition monitoring schedule<br>d. Assess understanding- recommend Teach back approach | | | |
| | | | |

| **Predict what will happen when the test is carried out** | **Measures to determine if prediction succeeds** |
|---|---|
| 1. | 1. |
| 2. | 2. |
| 3. | 3. |
| 4. | 4. |

DO: Describe what actually happened when you ran the test

Study: Describe the measured results and how they compared to the predictions

ACT: Describe what modifications to the plan will be made for the next cycle from what you learned

Pathways Project (adapted from IHI.org)


# Active Medical Management without Dialysis Pathway

## SECTION B: RESOURCES FOR PATIENTS


Insert your organization's logo here if you wish to co-brand

# Active Medical Management without Dialysis:

# Making a Choice to Live Well Without Dialysis

As your kidney disease gets worse, you will start talking with your healthcare team about the choices you have for treatment. These choices may include dialysis or active medical management without dialysis, sometimes also called "conservative management." Your team will help you make your decision by answering your questions and giving you the information you need to understand your choices. Whatever treatment you choose, the team knows that this is a very personal decision and will support whatever decision you make.

The information in this handout will help you understand what active medical management without dialysis is, why you might want to choose it, and what you can expect if you do choose it.

## What is active medical management without dialysis?

Active medical management without dialysis is for those who choose not to include dialysis as part of their treatment plan. It means that you will work closely with your kidney doctor and healthcare team to:

- Prevent and treat the symptoms and complications of kidney disease
- Protect and maintain the kidney function you have left
- Receive supportive medical and psychosocial care when needed
- Help you plan for the future

The goals of active medical management without dialysis are for you to as long and as well as possible without dialysis, be as comfortable as possible, and have a good quality of life.

## Why choose active medical management without dialysis?

Dialysis is not for everyone. For example, being older and having other medical conditions may mean that dialysis will not help someone live longer or improve their quality of life.

For some patients, the side effects of dialysis may even reduce their quality of life or increase their suffering. Dialysis may cause symptoms like cramping, fatigue, and a "washed out" feeling that some patients describe as "unwellness." Dialysis will not treat other medical conditions (e.g., diabetes, heart conditions, lung conditions, circulation problems, arthritis, and chronic pain). Some patients may not like the time and expense spent in travel to and from the dialysis center, the long hours (usually four) on dialysis three times per week, and a decrease in time for other enjoyable activities including exercise.

For these reasons, active medical management without dialysis may be a better choice of treatment for some people.

## What can I expect if I choose active medical management without dialysis?

Together with your healthcare team you will:

- Talk about what is most important to you and learn what your healthcare goals are. Treatment will focus on helping you reach those goals.
- Have symptoms regularly monitored and treated.
- Have blood work done only as needed to meet treatment goals.
- Take medications to suit your needs and goals.
- Learn more about what symptoms to expect as your kidney function decreases and how to treat them.
- Decide where you want to live as your illness progresses.
- Develop an action plan to avoid unnecessary emergency department visits or hospital admissions.
- Speak with your loved ones and healthcare team about your wishes for your treatment choices in the future. This is called Advance Care Planning.
- Learn about and complete advance directives and medical orders that can help you receive the treatment you want at the end of life
- Be given information about preparing a will and making funeral arrangements.
- Find resources in your community to support you and your loved ones.

**What support can I get while making the decision to choose active medical management without dialysis?**

For most patients, it is important to involve family when deciding if active medical management without dialysis is the right choice for them. It is also important to ask your healthcare team for information and support when you feel that you need it. If you wish, a family meeting can be arranged with your doctor, social worker, and others from the healthcare team. The family meeting is to support you, to answer questions, and hopefully, help relieve concerns. For many people, knowing their family understands and respects their wishes brings a great deal of relief and peace of mind.

The process of reaching your decision may be an emotional one for you and your loved ones. Everyone reacts differently when they are told their kidneys are failing. This is normal and expected. Some of the emotions you or your loved ones may feel are:

- Sadness/grief
- Fear
- Anger
- Relief
- Confusion

Over time, these emotions usually lead to acceptance and peace with the decisions you end up making. However, sometimes these emotions can be too much. Talk with your healthcare team- they can help. You may also be referred to other healthcare professionals (see below) for assessment, advice, or counseling as needed.

**Social Workers** help with many issues, from family support to financial and legal needs. A social worker is a member of your healthcare team.

**Palliative Care** focuses on improving the quality of life by preventing and/or relieving some of the symptoms seen with life-threatening illnesses. This is done by identifying, evaluating, and treating pain and other physical symptoms, and addressing psychosocial and spiritual issues. Palliative care starts early in the course of illness. Palliative care works with other therapies that are meant to help a person live longer. It offers a support system to help:

- You live as actively as possible until you come to the end of your life
- Your family cope during the illness and with their own grief or sorrow

## Once I choose active medical management without dialysis can I change my mind and try dialysis?

Yes. The decision is yours. You have the right to choose the treatment that you think will help you the most. Your healthcare team will do everything they can to make sure that you know in what stage of illness you are, how different treatments may affect your health and sense of well-being, and what treatment choices you have. Your healthcare team will support you in the treatment choice that most closely meets your goals for how you want to live and how you want your symptoms managed.

If you decide to try dialysis, ask your healthcare team about a time limited trial. This means you try dialysis for a certain period of time, such as two weeks to a month, and then discuss again whether it is the right treatment choice for you.

## How long will I live?

How long patients with kidney failure who decide not to receive dialysis treatments live is based on how much kidney function they have and how quickly it gets worse. You may have weeks, months, or even years ahead of you to live. Some factors that affect how long you will live include:

- Kidney function/GFR (Glomerular Filtration Rate)
- Protein in the urine
- Other illnesses such as diabetes and heart disease
- Lifestyle (e.g., weight, exercise, diet, blood pressure)

## Where to get more information

CKMCare is a Canadian site with comprehensive information about medical management without dialysis, which is called "conservative kidney management" in Canada.

Conservative Kidney Management: https://www.ckmcare.com/Pathway/AtAGlance

This site has an excellent on-line tool to help patients decide between dialysis or medical management without dialysis (called conservative kidney management): https://www.ckmcare.com/ckmpathway/pathwayintroduction

**Looking Back on Your Life**

After reading this you may find that you have mixed emotions, thoughts, and questions about your kidney disease, your life, and what is most important to you. This is a normal reaction. It is important to speak with your loved ones or somebody you trust to help you work through these thoughts and feelings. If you are interested in leaving your life story for your loved ones (through writing, artwork, making a recording, etc.) your healthcare team can support you while you do that.

You may find that writing down your thoughts, feelings, or questions will help guide your talks with your doctor and healthcare team.

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*This material is for information purposes only. It should not be used in place of medical advice, instruction and/or treatment. If you have questions, speak with your doctor or appropriate healthcare provider.*

Coalition for Supportive Care of Kidney Patients

# GREEN PATHWAYS FOLDER

**Take this folder with you if you go to the emergency room or hospital**

## Active Medical Management without Dialysis Pathway

*Living well without dialysis*

This folder should contain:

1. Pathways Patient Action Plan
   - What to do, who to call, if your symptoms get worse
2. Healthcare Professional Acute Action Plan
   - Information to help other doctors treat your symptoms
3. Letter to Emergency Care Providers
   - Tells emergency providers you don't want dialysis treatment
4. Your Advance Directive
   - If you can't speak for yourself, this tells doctors who should make decisions for you and what kind of care you want
5. Medical Orders for Life Sustaining Treatment (MOLST)
   - Your doctor fills this out after talking with you to tell other doctors what treatments you do and don't want at the end of life

Coalition for Supportive Care of Kidney Patients

Place your organization logo here

Patient label placed here or fill in this information.

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

# My Symptom Action Plan

**What is an action plan?**

An action plan helps you prepare for a time when your kidney function gets worse. This plan will help you: know whom to call (SUPPORT), which medication to take (SYMPTOM) and what to do in an EMERGENCY.

| SUPPORT | SYMPTOMS | EMERGENCY |
|---|---|---|

## SUPPORT:

My Family Physician: _____ Phone Number: _____

Fax Number: _____

My Kidney Doctor: _____ Phone Number: _____

Fax Number: _____

My Chronic Kidney Disease Clinic: _____ Phone Number: _____

After hours number:_____

My Home Care Case Manager: _____ Phone Number: _____

My Pharmacy: _____ Phone Number: _____

Family member/friend

If you are living at home and require daily assistance (with showering/dressing/toileting/medication), we strongly encourage you to have **homecare or hospice** 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, if you can no longer manage at home.

It is also important that you have engaged in **advance care planning**, and that you have an advance directive and a medical order form in your **Green Pathways Folder** at home. For further information, please speak to a clinic nurse.

## 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, reduced urine, 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.

Coalition for Supportive Care of Kidney Patients

# My Symptom Action Plan

Place your organization logo here

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

| |
|---|
| **Pain Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Shortness of Breath Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Nausea/Vomiting Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Restlessness/Confusion Medication:** _____<br>Regular Dose:<br>Breakthrough Dose: |
| **Any Other Symptom(s)** (Ie. Hyperkalemia) _____<br>**Medication:** _____<br>Regular Dose:<br>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 your family physician, home care case manager or Chronic Kidney Disease Clinic first**. They might be able to give you guidance about your medicine and how to address your emergency.

If needed, the above people can access your Kidney Supportive Care team on your behalf. While working together with your care team, Emergency Medical Services (EMS) professionals will attempt to treat your palliative symptoms (such as shortness of breath or pain) in your home as directed above.

Depending on the situation and **your wishes**, EMS personnel may need to transport you to the hospital for further testing or treatment. Make sure to take your green Pathways folder with you to the hospital.

**If you are unable to reach your family physician, home care case manager or Chronic Kidney Disease Clinic, and your symptoms are severe, phone 911.**

- Tell the EMS personnel **in your home** that:
  - You have end stage kidney disease
  - You have **CHOSEN active medical management without dialysis** of any kind.
  - You are receiving **palliative care.**
- Have your green Pathways folder ready to give to EMS, including your **Symptom Action Plan** and the **Health Care Professional (HCP) Action Plan**.

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

# Health Care Professional Acute Action Plan for Symptomatic Patients on the Active Medical Management without Dialysis Pathway

**Patients: PLEASE CALL US FIRST at_____.** 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 **active medical management without dialysis**. Keep this sheet in your Pathways Action folder.

**Health Care Professionals:** The following are recommendations only to be discussed with the patient's kidney supportive care team**.** These guidelines and rationale are commonly used for acute management for patients with End-Stage Kidney Disease who have chosen NOT to undergo dialysis.

| Symptom: | Suggested Pharmacological Treatment: | Rationale for Patients with End-Stage Kidney Disease: |
|---|---|---|
| **PAIN** | 1. Fentanyl 12.5 mcg SC/IV<br>2. Hydromorphone 0.2 mg SC/IV (0.5 mg PO) | Fentanyl is fast-acting, has a short half-life, and is a preferred opioid for kidney failure. **Note that morphine is not recommended for patients with end-stage kidney disease.** Even if a patient is actively dying, metabolites can accumulate and contribute to toxicity. |
| **SHORTNESS OF BREATH** | 1. Furosemide 80-160 mg IV<br>2. Fentanyl 12.5 mcg SC/IV<br>3. Hydromorphone 0.2 mg SC/IV (0.5 mg PO)<br>4. Lorazepam (Ativan) 0.5-1 mg PO/IV | **The most common cause of breathlessness in this patient population is pulmonary edema.** If the patient is still short of breath after furosemide treatment, consider opioids. **Opioids are the most effective drugs for the treatment of breathlessness in end-stage kidney disease.** Due to its fast action, fentanyl works well for breathlessness. **It is a preferred opioid for end-stage kidney disease.** |
| **NAUSEA/ VOMITING** | 1. Ondansetron 4 mg PO/IV<br>2. Metoclopramide 5-10 mg PO/IV<br>3. Haloperidol 0.5–1 mg IV | If ondansetron is ineffective, consider metoclopramide 5-10 mg PO/IV. If nausea persists, consider haloperidol 0.5–1 mg PO/IV. Do not give both haloperidol and metoclopramide: both are dopamine antagonists and can accumulate in end stage kidney disease. |
| **RESTLESSNESS/ CONFUSION** | 1. Haloperidol 0.5–1 mg IV<br>2. Lorazepam 0.5-1mg IV | Haloperidol can accumulate in End Stage Kidney Disease. The dose is typically reduced by 50%. If agitation or restlessness persists, consider lorazepam 0.5- 1mg IV. |

Patient: _____ Family/Friend Name and phone: _____

Family Physician:_____ Phone & Fax: _____

Kidney Supportive Care Case Manager:_____ Phone Number: _____

Chronic Kidney Disease Clinic:_____ Phone Number: _____

Pharmacy:_____ Phone Number: _____

Nephrologist:_____ Phone & Fax: _____



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Coalition for Supportive Care of Kidney Patients

Date

Dear Emergency Department Physician, Nurse, and/or First Responder,

This patient, _____, has advanced chronic kidney disease and **has chosen not to have dialysis.** This decision has been made after lengthy discussion with the patient, family, and health staff team about the patient's values, preferences, and goals. S/He is now being followed by the **Active Medical Management without Dialysis Program** at the Chronic Kidney Disease (CKD) Clinic at [clinic name].

S/He has asked me to provide health care providers who may treat him/her in the future with this letter. The patient has requested that s/he receive treatments and medications to promote comfort, but NOT dialysis, CPR, intubation, mechanical ventilation, vasopressors, and ICU care. A state-specific medical order form such as a Physician Orders for Life-Sustaining Treatment (POLST) with these orders is included with this transfer packet. Please call me (my covering physician) at any time of day or night if you have questions about this patient's treatment and how to honor the patient's wishes. My cell phone number is_____.

Thank you for treating him with respect and compassion.

Sincerely,

[name of nephrologist]
Nephrologist
Active Medical Management without Dialysis Program
Chronic Kidney Disease Clinic, [institution name]

Cc: all specialists involved



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Include Patient's up to date and valid Advance Directive in green Pathways folder.

Forms valid in each state are available from:
1) PREPARE for your care:
https://prepareforyourcare.org/advance-directive

PREPARE has easy to read forms in several languages. You can download the form for your state for free.

OR

2) CaringInfo: https://www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives/downloading-your-states-advance-directive/

Caringinfo has free downloads of the advance directive form for each state.

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Include completed POLST/MOLST or other medical order.

State-specific POLST/MOLST forms are available here:

https://polst.org/resources/resource-library/?pro=1