# CKD CONDITIONS & SYMPTOMS CURRICULUM

*This document serves as a guide for care managers to walk patients through the Chronic Kidney Disease (CKD) educational program. This document offers tips and resources for your conversations with patients to help you and them succeed. Patients will receive printed handouts from time to time. They may want to get a folder or a notebook where they can take notes. Encourage patient to get in the habit of bringing notebook to doctor visits.*

LEVEL 1

**Just Starting.** Patient might not know much about their illness or how to manage it.

## GOALS FOR LEVEL 1:

Individual becomes self-aware of their own behaviors and symptoms. Focus coaching on the relationship between symptoms and behaviors, building self-confidence and awareness. The individual should choose the area(s) they want to work on.

**Level 1: I**deally weekly calls, 5-7 minutes. (Consider first call of the month lasting 20 minutes but only spend 7 minutes on a specific coaching task – the remainder of the time in relationship building and reviewing the overall coaching program.)

**Level 1, Goal 1:** ⟶
**START HERE to help the patient learn basic information about their diagnosis**
(GOOD FIRST OPTION)

Review the handout ***"The Basics: Kidneys and Chronic Kidney Disease."*** This is two pages long. Make note of topics the patient would like to learn more about in future calls. Any questions that are unanswered should be written down for the patient to discuss with their doctor.

### Major points from this handout:

1. **What is the major job of the kidneys?** "To remove waste products and extra fluids from the body, in the form of urine."
2. **How do they remove the wastes and fluids?** They filter the blood.
3. **What does it mean when someone has chronic kidney disease?** "Chronic kidney disease or CKD is a condition in which the kidneys are damaged and cannot filter blood as well as they should."
4. **How does the doctor know I have chronic kidney disease?** CKD may not cause any symptoms. CKD is diagnosed using tests of the urine and blood.
5. Patients might note that they continue to urinate a normal amount, or alternatively, that they leak urine. Chronic kidney disease does not decrease the amount of urine until it is very advanced indeed. Leakage of urine reflects a problem with the bladder, not the kidneys.

## Level 1, Goal 2: Promote awareness of language of CKD and CKD risk factors

Discuss what the kidneys do to keep you healthy using the handout ***"Kidney Jobs and Problems Caused by CKD."*** We have reviewed that the main job is to filter wastes and extra fluid from the body, but there are other jobs performed by the kidneys. "Hormone" referred to in this handout means a chemical messenger used by the body.

Discuss what other problems arise when kidneys are not working using the handout ***"Kidney Jobs and Problems Caused by CKD."*** Kidney disease has impacts on other areas of the body.

Discuss what it means when people talk about the risk factors for chronic kidney disease using handout ***"Risk factors for Kidney Disease."*** Review the risk factors and highlight any that the patient has.

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## Level 1, Goal 3: Build knowledge about the tests used to assess kidney disease, and terms and numbers the care team uses to describe the patient's kidney disease.

Together, review the document ***"Estimated Glomerular Filtration Rate (eGFR) and Urine Albumin: Creatinine Ratio (ACR): Keys to Understanding How Well Your Kidneys Are Working."*** Discuss any misconceptions that were uncovered.

Discuss the individual's **eGFR**, **CKD stage**, and **ACR numbers**. Stress the importance of knowing your numbers and why each number is important. Make a plan to ask the nephrologist for these numbers at the next visit. Patient may want to plan to track these numbers over time. The stage of CKD that they were told by their doctor might not be accurate! Use the handout and their eGFR and ACR numbers (if known) to determine the G/A staging.

LEVEL 2

**Aware, But Confused.** Patient knows they're sick, but they aren't sure how to get better.

# GOALS FOR LEVEL 2:

Building knowledge and confidence. Individuals lack confidence and an understanding of their health or recommended health regimen. At this level, the person is struggling and becoming aware. The patient may have some knowledge, but large gaps remain, so review from Level 1 is built into Level 2. They are willing to set some simple goals, as they recognize they can do more.

**Description:** Increase in Knowledge, Initial Skills Development. Individuals develop the knowledge, skills, and confidence to master new self-management competencies. Coaching should focus on helping the individual learn to monitor symptoms, behaviors, and adverse triggers – and adjust accordingly. Focus on taking small steps.

Level 2 starts people thinking about steps they can take to take control of their kidney disease. This is planning phase: gathering information, noticing patterns, setting priorities. **At the end of Level 2, they should have the knowledge to understand where they are currently and where they'd like to be. They should have in mind an area they'd like to work on, and be excited to make a change.**

## Level 2, Goal 1: Review and solidify knowledge about CKD acquired in Level 1

***Handout: "Chronic Kidney Disease: Understanding and Taking Control"***

This is a different resource than is used in Level 1. While some of the content is a review, the language is slightly different. This mimics the experience of talking to multiple doctors, who can explain things differently (and have differing opinions). Any apparent conflicts can be discussed between the patient and their nephrologist.

- Review **definition of CKD.**
- Review **important jobs the kidneys do**.
- Kidney disease often presents without symptoms. Review **possible symptoms** and **make a plan to discuss any concerns with their nephrologist** at the next visit.
- Review **risk factors for CKD** and **note which risk factors the patient has**. Does the patient understand the cause of their kidney disease? Make a plan to discuss with their nephrologist to check their understanding.
- Review **complications of CKD** and **note which are of concern to the patient**.
- Review the **tests that are used to diagnose and monitor CKD**: the eGFR and ACR. There are some additional tests that are often used. Do they have questions about these tests to ask their nephrologist?

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## Level 2, Goal 2: Learn about strategies & targets for treatment in people with CKD

***Handout: "Chronic Kidney Disease: Understanding and Taking Control"*** *[same as above (first half of the document is review; second half introduces new information)]*

- **Go over the four goals of managing CKD:** manage the disease causing the CKD, slow the loss of kidney function, reduce cardiovascular risk, and treat complications of CKD.
- Discuss the importance of using **more than one strategy to control CKD** – medications plus making lifestyle/behavior changes.
- There are multiple medications that are often used to treat kidney disease. (There is a whole curriculum to learn more about medications, so there is less detail here. Patients may choose to delve into medications as their next section to progress through the curriculum.) Note the categories that are commonly used: **ACEi/ARBs, SGLT2i, MRA, and statins.** There are multiple medications in each of these categories. Make a plan to ask their nephrologist which of their medications falls into each of these categories, or if they would benefit from adding medications.
- Discuss how **smoking and other tobacco products contribute to CKD** and the complications of CKD. Does the patient smoke? Are they willing to cut back or quit? (Just get them thinking about it for now. There is a smoking cessation section of the curriculum they can prioritize for next steps.)
- Discuss why being **overweight** (too many food calories plus inactivity) **contributes to CKD.**
- Review **potential lifestyle recommendations** for taking control of their CKD risk factors. Encourage patient to start thinking about what changes they could prioritize.
- Prepare for the **next appointment with their nephrologist**. Go over the list of suggested questions. This is too many questions to address in one appointment – **prioritize the top three**. Some information about labs and staging will probably be available in the patient chart.

## Level 2, Goal 3: Increase skills to manage CKD

***Handout: "How to Measure BP"***

- Encourage patient to acquire a **home blood pressure monitoring device**. Learn how to use it; put together a plan to measure two or three times per week. Track results using a tracking tool.
- Discuss how to **properly measure weight**. Check weight once a week and track over time. Get a feel for how activity and nutrition impact weight changes.
- Discuss the importance of **visiting nephrologist** and **getting tests on regular cadence**. Identify challenges in scheduling and attending visits. Discuss ways to overcome obstacles: virtual visits? Scheduling multiple visits ahead? Ask nephrologist what the recommended visit cadence is for the patient's stage of CKD.

## Level 2, Goal 4: Connect behavior and CKD risk factors

Encourage individual to pay attention to the time spent each day doing things that can worsen CKD risk (smoking, being inactive, eating high salt/fat foods). Start thinking about prioritizing changes they can make.

Discuss the risk factors for CKD – do they cause other health problems as well? (examples: lung cancer, high cholesterol, heart disease, diabetes, stroke, heart failure) Understand that there are lots of extra health benefits that come with making positive changes.

LEVEL 3

**Getting Better.** Patients are beginning to take action and build self-management skills. They could still use some help.

# GOALS FOR LEVEL 3:

Level 3 patients are taking action, building self-management skills, are goal-oriented, and strive for best practice behaviors. However, they may lack the confidence and skills to support their behaviors. Ideally, interventions are **every 2-3 weeks**, and last about **10-15 minutes**. Focus on what is or is not working, overcome barriers, take next steps, and set new goals.

*NB: To make sure the requirements for 20 minutes are met, consider a call early in the month that meets length criteria, but not all of that 20 minutes should be spent on goal-directed coaching. You can spend 5 minutes on relationship building, medication updates, etc. If there are goals that would benefit from more frequent short check-ins, set a time later in the month for that additional call.*

Individuals initiate new health-promoting behavior(s) and work to further refine techniques to monitor and adjust. Coaching should focus on **providing encouragement, noticing successes,** and **problem solving**. Encourage use of **SMART+ goals template** for best success.

*"I'm part of my health care team."*

## Level 3, Goal 1: Initiate new, healthy techniques to manage CKD

***Handout: "SMART+ Goals Worksheet"***

- Work with the individual to recognize that treating CKD is a result of **taking medications correctly** and **making lifestyle/behavior changes**. Potential areas for change were discussed in Level 2. **What change would patient like to prioritize at this time?**
- Introduce **SMART+ Goals Worksheet** and work to complete it for the desired change area. Plan to discuss with nephrologist or PCP at next visit to get their input: Is this a good first choice? Is there assistance the medical team can give? Review remainder of curriculum for specific content on the chosen target.
- Keeping in contact with the nephrologist is important for overall kidney health management. Confirm recommendations from nephrologist about **visit frequency**. Set **calendar reminders for appointments** and **lab draws**. Work on making sure patient has **access to their medical chart**. If they're unable to use a computer, who can assist them?

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## Level 3, Goal 2: Self reward for improved CKD care

***Handout: "Self Rewards"***

- Together, make a list of inexpensive and fun ways to **self-reward for behaviors that lower blood pressure**. Avoid rewards that involve junk food, smoking and being inactive!
- Encourage self-rewarding when the individual meets an interim (baby step, small) goal. Examples of interim goals: meets weekly physical activity goal for the week; doesn't exceed daily calorie goal for the entire week; quits or cuts back smoking/smokeless tobacco for a week; limits salt/sodium to less than 1,500mg per day for one week; loses a pound or reduces BMI by 1/2 point; adheres to medication schedule for the week

LEVEL 4

**Doing Great.** Patient is in charge of their health and now needs support maintaining it.

# GOALS FOR LEVEL 4:

Level 4 is about **maintenance**. Individuals have adopted new behaviors to take charge of their own health, but they may need help maintaining these behaviors in times of stress.

Coaching should **focus on the issues that make it hard to stick to correct behaviors** and to **help the individual troubleshoot**. Individuals are asked to solidify new behaviors, identify specific barriers, plan how to overcome them, and work with personal challenges that may derail success.

## Level 4, Goal 1: Maintain healthy behaviors and continue on therapies to slow the loss of kidney function.

- Encourage individual to **maintain a healthy blood pressure** and to **monitor BP at home**
- Encourage individual to maintain healthy lifestyle behaviors such as:
  - Continuing to be **physically active**: 10,000 steps each day or 30 minutes of brisk activity (walking) at least 5 times each week
  - Continuing to **not smoke, vape, or use smokeless tobacco**
  - Continuing to **limit intake of ultra-processed foods and caloric drinks**

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## Level 4, Goal 2: Learn techniques to get back on track

***Handouts:***
***"Using Meditation to Get Back on Track"***
"***Getting Weight Loss Back on Track"***
"***How to Stop Bad Habits from Derailing Your Progress"***

- Together, brainstorm the many ways and opportunities that people can deviate from their plans to live a healthy lifestyle and adhere to the doctor's prescribed medication schedule.
- Together, identify the ways that are most likely to get the individual off track.
- Together, brainstorm ways to get back on track when they fall off. Try them out and see what works.
- Discuss relapse and that everyone falls off the wagon sooner or later. It's normal and expected.

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## Level 4, Goal 3: Learn skills to trouble shoot situations where it is difficult to manage diet, cope with stress, and stay physically active

- Together, identify upcoming potential threats to effective blood pressure management: weekend, holiday, financial problems, vacation, business trip, bad weather, family emergency, stressful situations, etc.
- Encourage individual to develop ongoing awareness of situations that could negatively impact healthy lifestyle and blood pressure control. Have a plan in place to proactively get back on track.
- Discuss difficult or stressful situations and reacting with health promoting behaviors rather than health harming behaviors (smoking, inactivity, overeating)
- Encourage individual to write up a plan for dealing with situations where it is difficult to retain positive lifestyle changes

***Handout: "How to Get Control of Emotional Eating" (similar content but specific to eating)***

## Level 4, Goal 4: Pursue healthy "stretch" goals

- Encourage individual to further increase daily step count to **optimize health and fitness**
- Encourage individual to **vary physical activity regimen**
- Discuss **limiting alcohol** to one drink a day for women or two drinks a day for men and note the positive effect on health
- Discuss finding a **partner or buddy** to renew/sustain interest in staying fit over the long haul
- Get involved in **advocacy for kidney health**. Look at the local chapter of the National Kidney Foundation and make a plan to participate virtually or in-person.
- Encourage individual to **write up a plan** for dealing with situations where it is difficult to retain positive lifestyle changes


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