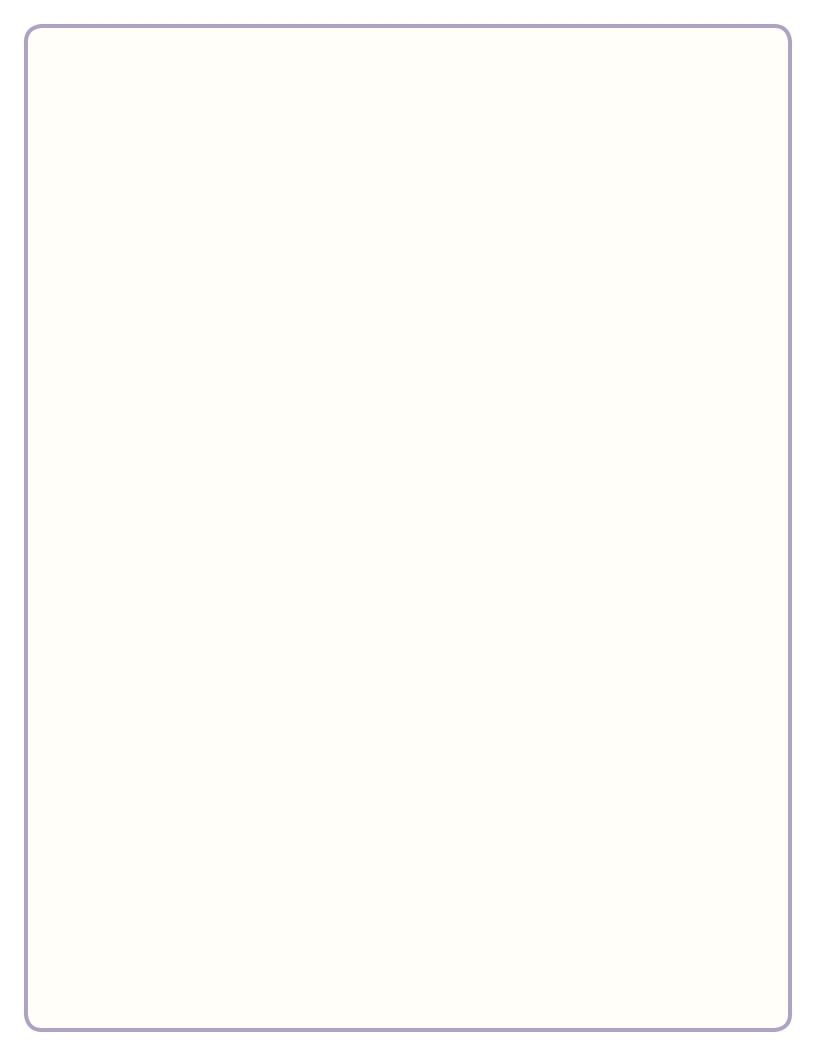


# **CHRONIC KIDNEY DISEASE**

**FACILITATOR RESOURCE** 



## **NOTES**

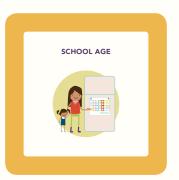
## **RESOURCES MENU**

- 1. Your Kidney Health Team
- 2. Meet Your Kidneys!
- 3. Balance
- 4. Connections
- 5. Healthy Eating
- 6. Being Active
- 7. Taking Medicines
- 8. Healthy Blood
- 9. Bone Health
- 10. Blood Pressure
- 11. Acid Balance
- 12. Growth

## 13. CHRONIC KIDNEY DISEASE

- 14. Family Coping Resources
- 15. My Coping Resources
- 16. Glossary







## 13. GLOBAL LEARNING OBJECTIVES

By the end of this session, the children and their family will be able to:

- anticipate that medical and physical changes occur with CKD progression
- apply medical recommendations to delay and / or slow progression

## KIDNEY HEALTH MODULES DESIGN OVERVIEW

This material was compiled and designed to meet the needs of the diverse children, their families, caregivers and the health care providers who will be facilitating learning about how to live well with chronic kidney disease.

The design incorporates findings from research on providing health education information to children and adults. A number of families agreed to allow the consultant observe their appointments and interview them about learning about and managing their or their child's chronic kidney disease. In addition, health care providers received a questionnaire and were interviewed about their priorities for children and families in order to manage CKD effectively.

To determine initial topic areas, children and families were asked what was most important to know and most important to be able to do to manage their disease well. The Project Team considered what is required to manage CKD well from their perspective. From this information, topics were grouped into the resulting 16 topic areas. Certainly, for parents and children, "being able to do" things to manage CKD took priority over understanding so much about the disease.

Once the topic areas were determined, the consultant worked with pediatric nephrology health care providers to determine learning objectives for the 3 developmental stages and parents and caregivers.

Using plain language principles and best practices for developmental stage learning design, modules were designed to guide learners towards achieving the learning objectives.

Each module begins with an overview of all learning objectives. The learning objectives are informed by the Key Messages and Clinical Targets which are supported by Resource Materials for the facilitator for each module.

Each section of the module begins with reminders about your approach, appropriate for each developmental level. There is ample white space for you to write your own notes and ideas for delivery.

The Parent and Caregiver Resource provides highlights of the concepts and terms for each module as well as the full glossary for that module. There is also a listing of relevant online and library-available resources.

#### **FACILITATING LEARNING**

Facilitating learning puts the emphasis on the learners and their interests and abilities rather than on an outside entity. How does this affect what you, as the healthcare provider, do?

- Work with people where they are at.
- If families are not ready to make a change, they do not need to sit through the presentation of materials. You may want to just give the Activity Sheet to these people. Or you may wish to start a conversation about what the Kidney Health Team can do to help the family feel they are ready to make some changes.
- Use Motivational Interviewing techniques.
- Be careful not to ask for more than one change at a time.
- Not everyone will be able to understand or use the information in the same way. You may find yourself revisiting modules with some children and families repeatedly while others will go away and look into things on their own.
- You will be helping people learn how to manage the disease rather than learn about the
  disease and understand why the doctor or healthcare team is recommending certain types of
  management.

#### Connecting and Relating Learning

A key premise of this work is interconnections. As a facilitator, find ways of linking concepts and tools throughout the modules. As much as possible, concepts are built upon throughout the modules. For instance, in Connections we begin to talk about heart health and kidneys. In Blood Pressure, we build upon that knowledge and introduce the concept of perfusion.

#### Applying information

Encourage children and families to refer back to information and use the concepts and terms presented. Make sure they are holding the "story books" flipping through them and back and forth in a way that makes sense to them. The concepts and information designed are age-appropriate, clinically and medically accurate and meant to be applied. The Activity Sheets are designed for use people at all levels to reinforce vocabulary and concepts.

#### Visual Learning

The vast majority of people are visual learners rather than auditory learners. Interesting graphics that tell a story are a more effective way for many people to learn than either listening to information on its own or reading dense information. You will notice that the glossary terms are supported through graphics linked to concepts introduced in the modules.

#### **Literacy Levels**

In Manitoba, 40% of working adults have low literacy levels. Give people time. Let them contemplate the graphics. Keep your language plain.

#### RESEARCH KEY FINDINGS

## **Developmental Stages and Learning Design Key Points**

- Importance of play in learning and education for all levels.
- School-age: time to create and reinforce healthy rituals.
- Adolescence: begin to share consequences but limited.
- Delivery of learning is key: recommendation to embrace motivational interviewing as intervention approach.
- Use of transtheoretical / stages of change model.
- HCP as facilitator of learning.

#### **Child / Parent Consultations Summary Key Points**

- The "how" needs to come before the "why" in educating. Some patients and families may never get to the "why."
- Global approach to living healthily and move towards the rationale.
- The lived experience is how we need to think about the learning and educating.
- Appreciation for visual cues and teaching aids.
- Need for useable, family-friendly diet information:
  - shopping lists and pantry list.
  - meal plans for breakfasts, lunches, dinners, snacks that are kidney health friendly and will work for whole family.
- Patients and families do and want to learn from each other.
- Value in emailing nurse clinician.

## Best Practices for Health Education Summary Key Points

- Emphasis on action-oriented teaching: what people need to do and how to do it.
- Put positive in front of negative: provide hope rather than feed despair.
- Use simple pictures and graphics to display proportions.
- Plain language is not "dumbed down": it is simply clear.

For more information, contact any member of the Kidney Health Advisory Group:

Angela Chotka, MA Julie Strong, BN Tom Blydt-Hansen, MD Diane McKenty, RN

## **DEVELOPMENTAL LEVEL OBJECTIVES**

By the end of this session:

## The Pre School Age Child will be able to:

- a) identify they go to the kidney doctor
- b) state "how I feel today"

**Possible activities include:** pictures of feeling sick, well, sad, scared, etc.

## The School Age Child will be able to:

- a) describe how they are feeling today
- b) identify if they are feeling differently from how they usually feel
- c) respond to screening for CKD symptoms
- d) identify the routines in their life (brushing teeth, sleeping, bathing, going to school...)

#### Possible activities include:

## The Adolescent will be able to:

- a) identify health status of heart, brain, bones, muscle
- b) recognize health care team as monitoring status
- c) adapt to changes in health care status using personal recipe
- d) negotiate changes in routine with adults
- e) keep a symptoms diary

**Possible activities include:** an activity to show change is an inevitable process, for example: growing a plant, a calendar showing season changes

## The Parents and Caregivers will be able to:

- a) show routines in their children's lives
- b) understand that changing medical care is a normal part of managing chronic illness
- c) negotiate appropriate changes in routine with children

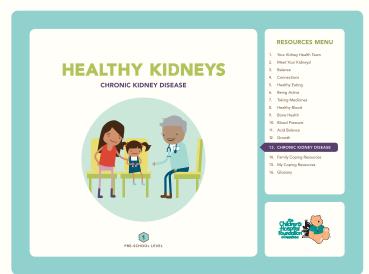
#### **KEY MESSAGES**

- 1. This module is targeted more specifically to children/families with established renal insufficiency (Stage 2-5), where there is the expectation of CKD progression over time.
- 2. CKD is a chronic and in some cases progressive disease that will require life-long treatment and support by the kidney health team. Some will progress to the point of needing renal replacement therapy.
- 3. Kidney disease progresses toward end-stage at different rates depending on the underlying cause and the achievement of clinical targets to delay progression.
- 4. Kidney team focus is on health maintenance, monitoring of progression of kidney function and anticipation of clinical needs as kidney function declines.
- 5. Multiple systems are affected by CKD progression and may differ in their degree of involvement between patients, and also differ in regard to how patients experience it.
- 6. We are able to anticipate and screen for CKD co-morbidities that require escalation of treatment as functional capacity deteriorates for each system. Treatment targets are determined by benchmarking, which guide adjustments in treatment prescription.
- 7. Patients and families are considered as partners in understanding how kidney disease is affecting the person, how it is being experienced, and that this information is important in guiding treatment decisions. We must value the input of patients and families in evaluating their current status.
- 8. There is a dedicated kidney health team that specializes in the care of kids with more advanced CKD. The decision to use the CKD clinic for care is made jointly with the family.
- 9. A structured home environment will significantly enhance adherence to treatment and adaptation to changes that will occur as CKD treatment needs evolve. This includes meal times, sleep/wake times, school and hygiene (tooth brushing, bathing times).
- 10. Structure in the family home is an empowerment tool, a way to help manage and live better with the chronic illness.
- 11. It is important to not make the affected child "different", rather to reinforce inclusion of the routines associated with their kidney care into the whole family routine. This includes the home environment, diet restrictions, physical activity and similarities of family "rules" between siblings.
- 12. Patients are encouraged to identify and track symptoms that may be related to CKD progression and comorbidities, and to share these routinely with the kidney health team.
- 13. Patients need to be aware of symptoms that suggest progression toward end-stage kidney disease, and that these will influence choices regarding treatment and recommendations of the kidney health team.
- 14. A motivational interviewing approach is used to engage the patient and family in managing changing treatment requirements, and to improve adherence to therapy. This includes assessing readiness for change.
- 15. Parents or guardians are responsible for ensuring adherence to treatment plans that evolve with CKD progression. Parents should support teens in developing capacity and autonomy, and to integrate the treatment plan as part of their daily lives.

## **TARGETS TO BE AWARE OF:**

- 1. K-DOQI guidelines provide criteria for staging CKD progression
- 2. Standard testing panels are used in the monitoring of CKD co-morbidities
- 3. The CKD program has agreed-upon benchmarks (guided by the K-DOQI and KDIGO guidelines) to establish targets for treatment of CKD co-morbidities.
- 4. There is a standard psycho-social assessment by the social worker to evaluate the needs of each unique family dynamic
- 5. Stage of readiness for change as determined via motivational interviewing will determine what type of intervention is most appropriate at the moment.
- 6. Asking about symptoms is expected as part of each clinic visit

#### PRE-SCHOOL LEARNING



#### PRE-SCHOOL LEARNING OBJECTIVES

Remember ... children can use words and images to represent objects but are not yet reasoning logically.

## The Pre-School Age Child will be able to:

- a) identify they go to the kidney doctorb) state "how I feel today"
- **Possible activities include:** pictures of feeling sick, well, sad, scared, etc.

#### **MY APPROACH**

- 1. Review Motivational Interviewing.
- Assess where family is at re: Stages of Change.
   Acknowledge that Progression means change for the child and family.
- 3. Remind family that the Kidney Health Team and the child and family are on the same team.
- Acknowledge what children do or say. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 5. Ask questions to provoke thinking; describe pictures.
- 6. Provide hints to assist children when they are struggling with concepts.
- 7. Offer a variety of choices when children are trying to find the answer.
- 8. While your time is limited, try to give children and family time to think about the material and messages.

#### **LEARNING SUPPORTS**

Have you got the Learning Supports you might want to use?





 We are happy you are here at the Kidney Health Clinic!

What do you see in the picture?

## Options:

Yes, there are lots of people here to help you feel better.

Do you see other children? Yes, many other children come here too.

Yes, we check you so you can feel good. Do you know what part of your body we are checking?

2. We are here to help you. We are going to do a kidney check up.

We will measure how tall you are.

We will put a cuff on your arm and check your blood pressure.

We will check your body like feeling your tummy and listening to your heart.





## 3. Possible dialogue:

It's important to tell your kidney health team anything about how you are feeling.

We want to know how you are feeling so we can help you and your kidneys.

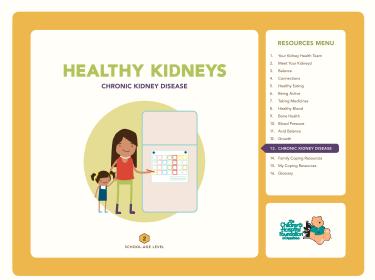
4. Our (Mom / Dad / Caregivers ) can help tell us how you are feeling.

Encourage parents / caregiver to fill in blanks.



We need to know how you are feeling. Sometimes you might want to just say "ok" but it is better if you can tell us more.

#### **SCHOOL AGE LEARNING**



#### SCHOOL AGE LEARNING OBJECTIVES

Remember ... children can think logically about concrete objects and can apply rules in a consistent way.

## The School Age Child will be able to:

- a) describe how they are feeling today
- b) identify if they are feeling differently from how they usually feel
- c) respond to screening for CKD symptoms
- d) identify the routines in their life (brushing teeth, sleeping, bathing, going to school...)

Possible activities include ...

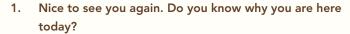
#### **MY APPROACH**

- 1. Review Motivational Interviewing.
- 2. Assess where family is at re: Stages of Change
- 3. Acknowledge that Progression means change for the child and family.
- Remind family that the Kidney Health Team, parents and child work together to create the best kidney health for the child.
- 5. Provide information, directly giving children facts, labels and other information.
- 6. Ask questions to provoke thinking; ask children to describe pictures.
- 7. Provide hints to assist children when they are struggling with concepts.
- 8. Offer a variety of choices when children are trying to find the answer
- 9. While your time is limited, try to give children and family time to think about the material and messages.

## **LEARNING SUPPORTS**

Have you got the Learning Supports you might want to use?





Yes, you are here to get check your kidneys.



You are here today to get your kidneys checked.
 There are many children who come and see us. We will do a check up and we will probably have to do some tests

These questions and test help us make you healthier.





## 3. Possible dialogue:

It's important to tell your kidney health team anything about how you are feeling and how it's different from usual.

We want to know how you are feeling so we can help you and your kidneys.

## 4. We need to know how you are feeling.

Sometimes you might want to just say "ok" or "fine" but it is better if you can tell us more.

Do you have an upset tummy? Do you feel sad? Do you feel tired? Do you have a headache? Are you itchy? How's your eating?





 Your (Mom / Dad / Caregivers ) can help tell us how you are feeling. Maybe they have noticed something that you didn't remember to say.

Encourage parents / caregiver to fill in blanks.

6. As time goes on, you might feel differently.

We try to help you feel as good as you can. We might change medicines, nutrition supplements or do tests to help you and your kidneys.

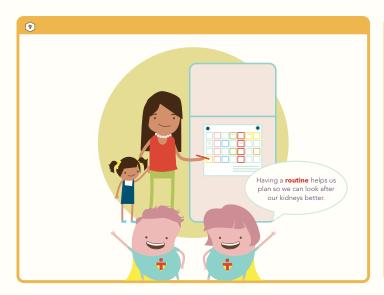




7. Can you think of some things you do everyday?

Give child some time to come up with ideas.

8. There are usually many things we do every day.
Look at the pictures. Are there some things you do everyday? Are there other things you do every day?



It can help us feel better when we know what will happen every day.

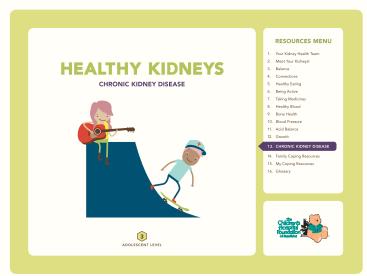
As your kidney disease changes, it helps to have some regular things we do every day. It helps us live well with chronic condition.



10. Over time, looking after your kidney health is just part of your routine. You have to do special things to look after your kidneys and someone else might have to do special things for another reason.

Remember we are here to help. We have worked with lots and lots of families who learn to learn to live well with kidney disease.

#### **ADOLESCENT LEARNING**



#### ADOLESCENT LEARNING OBJECTIVES

Remember ... many adolescents can reason abstractly and think in hypothetical terms

## The Adolescent will be able to attain \* School Age Objectives and:

- a) identify health status of heart, brain, bones, muscle
- b) recognize health care team as monitoring status
- c) adapt to changes in health care status using personal recipe
- d) negotiate changes in routine with adults
- e) keep a symptoms diary

### \* The School Age Objectives:

- a) describe how they are feeling today
- b) identify if they are feeling differently from how they usually feel
- c) respond to screening for CKD symptoms
- d) identify the routines in their life (brushing teeth, sleeping, bathing, going to school...)

**Possible activities include:** an activity to show change is an inevitable process, for example: growing a plant, a calendar showing season changes

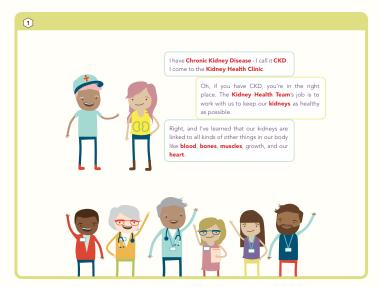
#### **MY APPROACH**

- 1. Review Motivational Interviewing.
- 2. Assess where family is at re: Stages of Change
- 3. Acknowledge that Progression means change for the child and family.
- Remind family that the Kidney Health Team, parents and child work together to create the best kidney health for the child.
- Acknowledge what the adolescents say and do.
   Model attitudes, ways of approaching problems and behaviours rather than telling them.
- 6. Ask questions to provoke thinking; describe pictures.
- 7. Guide, do not dictate. Youth want info so they can make their own decisions. Be patient. Don't be discouraged if your first offers of support is turned down. Give opportunities to use strategic thinking, reasoning and problem solving. Let them do some evaluation and monitoring of their understanding
- 8. While your time is limited, try to give children and family time to think about the material and messages.

## **LEARNING SUPPORTS**

Have you got the Learning Supports you might want to use?

Provide several options to choose from: alarms; link medications w/ activities (brushing teeth, etc); pill boxes; consolidate medications and times; apps; emergency supplies; how to take medications in public (school / with friends); pill swallowing will be referred to child life;



1. Do you know why you are here at this clinic?

Yes, to have your kidneys checked.

There is a team of people here to help you be as healthy as you can be.

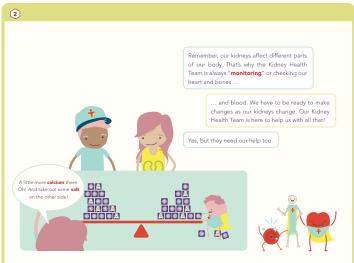
Do you remember learning about the right ingredients and recipes for many things in your body?

Give adolescent time to think.

What do you remember talking about before?

Possibilities include:

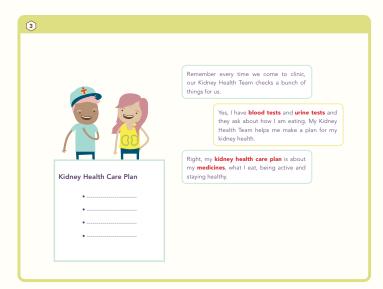
- Bone Health
- Growth
- Right Amount of Acid
- Healthy Eating
- Blood Pressure
- Strong Blood / Anemia

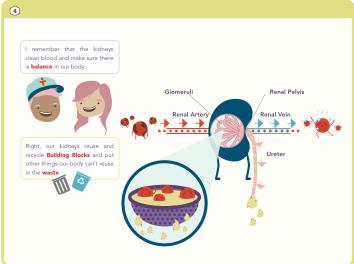


 We – your Kidney Health Team – are here to "monitor" your health. We do different tests and ask you questions so we can understand what is happening for you and your kidneys.

We will need to make adjustments to medicines and what you eat and drink and maybe some other things.

Sometimes, things can be changing inside your body without you really feeling any differently. Sometimes you will feel differently but sometimes you won't.





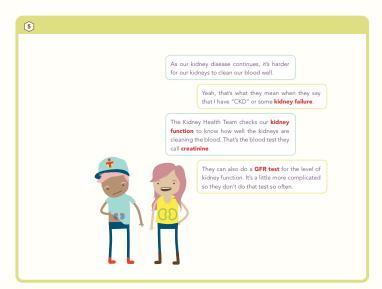
When you have a chronic disease, it becomes part
of your life over time. It should not be all of your life
but it is something that you likely have to pay some
attention to every day.

To live best with your chronic disease, you have choices to make about taking medicines, eating and activity.

What do you think about that?

4. Let's do a little review of different things we want to make sure you are paying attention to.

We are especially going to talk about your heart, bones and blood.





- 5. Do you remember what the kidneys do with blood?
  - Possibilities:
  - They help make it (yes, we will talk about that in a minute)
  - They clean it and make sure there is balance in our bodies with all our Building Blocks.
  - Kidney Disease can continue to develop so there are likely going to be changes to how well your kidneys work and how well they can clean your blood.
  - We keep testing your kidneys and adjust your medicines and food to help your kidneys do the best job they can.

Having strong bones make you grow better and get stronger. We each have our own special recipe for strong bones.

The recipe for strong bones has 5 main ingredients: calcium, phosphate, vitamin D and active Vitamin D and being active.

Kidney disease is a chronic disease. It can continue
to develop over time. Your Kidney Health Team is
always checking your kidneys for their level of kidney
function.

We can test your kidney function with a couple of different tests: creatinine and GFR.





 Based on the results from these tests, we make changes to your medicines and nutrition to keep your kidneys as healthy as possible.

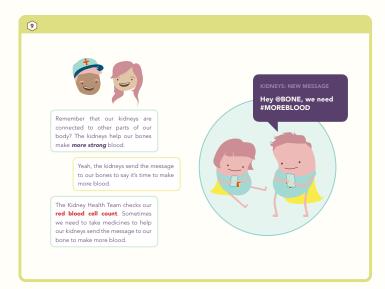
Of course, we need the best information from you too.

 All the adjustments and changes we make with your medicines and nutrition are to prevent uremia or help you feel better when you have uremia.

When there is waste in your body, we say you have uremia.

Uremia makes you feel sick and nauseated. Uremia can make you lose your appetite and can make it hard for you to grow.

\* Facilitator's note: Our goal is to prevent symptoms of uremia by delaying or preventing progression of kidney disease (failure).





We keep working with you to slow down your kidney disease as much as possible.

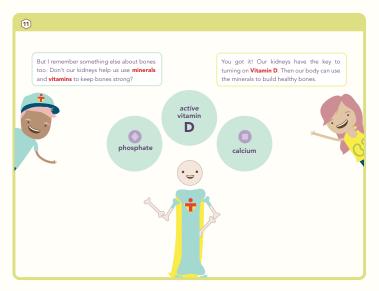
When we slow down your kidney disease, it helps your kidneys do all their jobs in the body and stay healthy as long as possible.

We are always checking targets to try and keep balance in your body.

10. Our kidneys are important for making more strong blood. Kidneys send the message to bone to tell Bone to make more blood. As kidney disease progresses or continues, our kidneys might need help making the message to send to our bones.

We might have to change some of your medicines to help your kidneys do this job well.

- \* Facilitator's Note: There are two concepts relating to blood: strong blood and more blood.
  - Erythropoeitin = More blood
  - Nutrition = Strong blood





 Review list of symptoms with child and parent.
 Emphasize that everyone might have different symptoms but it is important to watch for these ones.

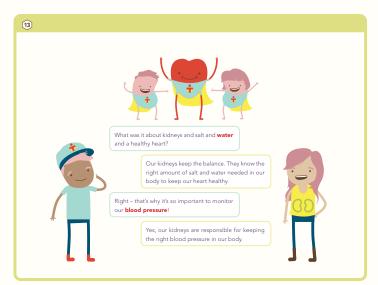
Ask the child who they talk to if they have symptoms or if things are not feeling right.

Remind them that medicines and nutrition might be changed to help them feel better.

 We check your Parathyroid Hormone levels to tell us if your body has enough Active Vitamin D. We also look at the levels of vitamins and minerals in blood tests.

Again, we will adjust your medicines and possibly your nutrition to help your kidneys help your bones.

\* Facilitators Note: Extra learning, if appropriate: We check your Parathyroid Hormone levels to tell us if your body has enough Active Vitamin D.





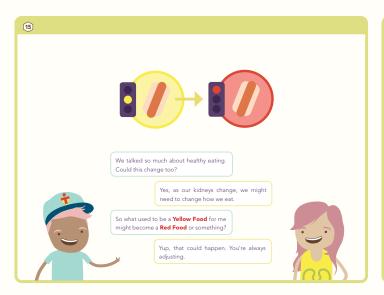
 Your body might give us some signs if you do not have the right amount of ingredients for strong bones.

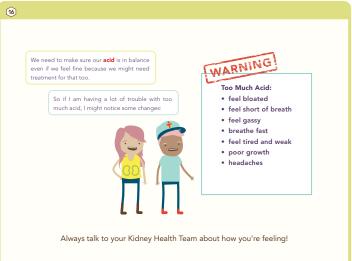
Signs to watch for include:

- having red eyes
- feeling itchy
- less growth than expected
- bones which can bend and break
- \* Facilitators Note: Will talk more about growth in Growth Module

14. One of the other things your Kidney Health Team will be monitoring is your blood pressure. The kidneys help keep the right blood pressure in our body so we have to check it regularly.

We adjust your blood pressure medicines to help control your blood pressure. We might also suggest changes to what you eat.





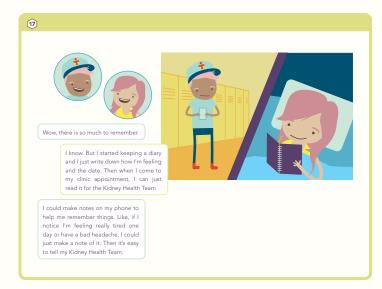
- Living well with a chronic disease is a lot about making adjustments. We make adjustments to medicines and exercise and also food.
  - \* Facilitator's Note: Check with child and family if there are specific concerns about diet that require addressing or reinforcing.

16. Another thing the kidneys do in our body is balance acid. Sometimes there can be side effects from the medicines to help your body balance acid so it is important you are telling us how you are feeling.

Check with child / family about side effects of medicines.

If you have too much acid in your body, you might have symptoms of metabolic acidosis. Let's check these symptoms and see if you have any.

If appropriate, check with adolescent.



17. It helps for all of us to write things down – then it's easier to remember. Sometimes we can look for patterns. If you can write down the date, how you feel and how you were eating, it can be really useful to help us help you.



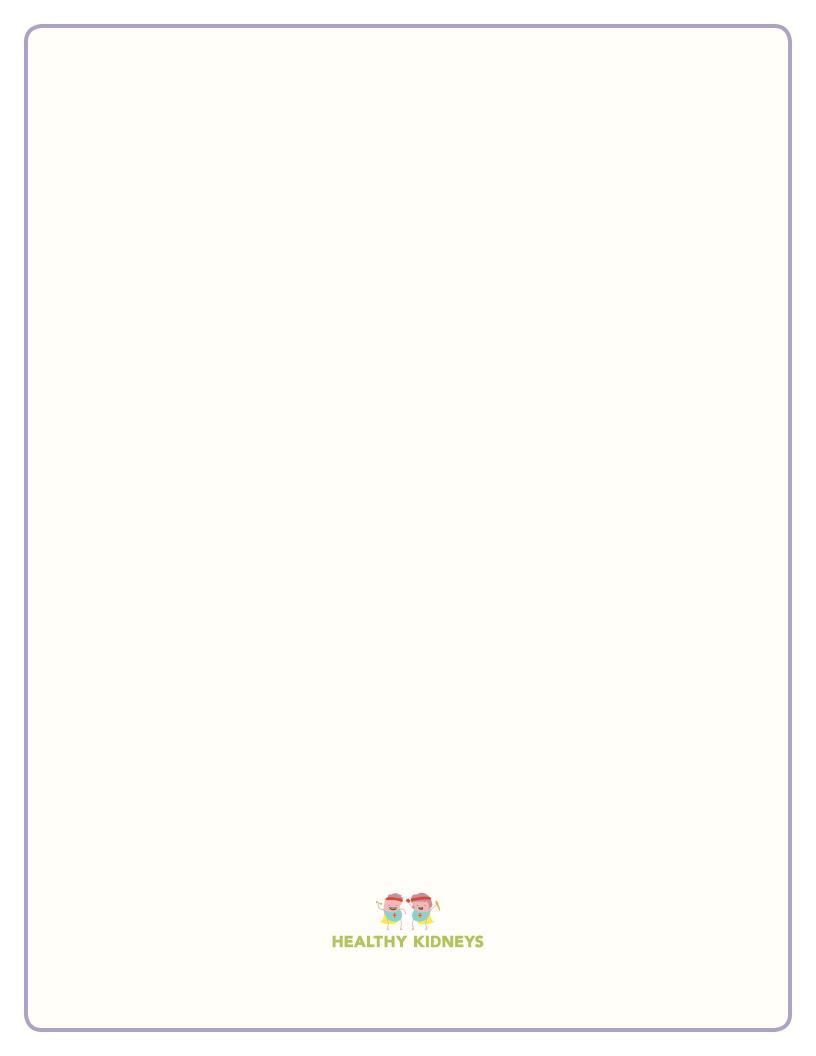
18. Initiate a conversation around adjusting to living with their chronic disease. State that everyone does things every day to stay healthy. Ask the child and their family what they do every day to live well with their CKD. The conversation might include discussion about how to ensure that the disease is not overtaking the child's, a sibling's or the family's life.



19. You know that living with your CKD is easier when you have a good routine. That routine helps you take medicines, get enough sleep, eat regularly and so on.

But, as your CKD changes – and it will change – you might need to change your routine too.

Your parents will help you adjust your routine.











Created by Julie Strong BN, Tom Blydt-Hansen MD, Diane McKenty RN, and Angela Chotka MA with Pediatric Nephrology (Children's Hospital Health Sciences Centre) and Chotka Consulting: Creative Balanced Solutions. With thanks to the Children's Hospital Foundation of Manitoba for their generous support.

For more information about this resource, please contact Pediatric Nephrology at 204-787-4947 or jstrong@exchange.hsc.mb.ca or the Children's Hospital Foundation of Manitoba http://goodbear.mb.ca