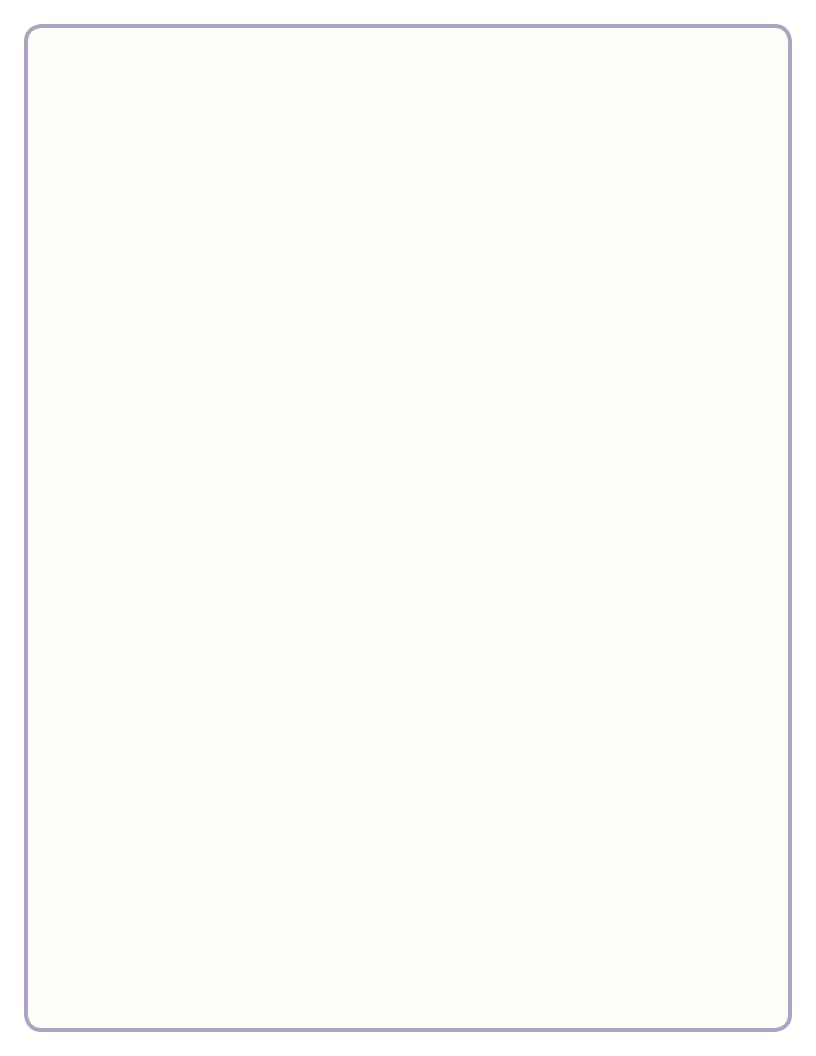


YOUR KIDNEY HEALTH TEAM

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







1. GLOBAL LEARNING OBJECTIVES

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

- connect the steps that make a beneficial clinic visit
- answer "what is this clinic for?"
- answer "why are you at this clinic?"
- identify clinic people and roles

Supports: repeated tour of clinic space for everyone.

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) understand they are coming for kidney checkup
- b) name key players by name
- c) have fun

Possible activities include: pictures of key players and roles; kidney twins visiting clinic on poster;

The School Age Child will be able to:

- a) understand and cooperate with having height, weight, blood pressure measured
- b) understand the nurse will check medications
- c) know that urine (pee) test helps nurse and doctor understand how healthy their kidneys are
- d) understand that blood tests help the nurse and doctor understand how healthy their kidneys are
- e) understand that the doctor will talk to them and do a check-up
- f) know that the doctor and nurse will be asking them questions
- g) know that the doctor will give Mom and Dad information on how to keep your kidneys healthy

Possible activities include:

The Adolescent will be able to:

- a) help check in
- b) give a history
- c) talk to the doctor and nurse
- d) understand they can speak privately with any member of their health care team
- e) remember medications
- f) get their next appointment slip
- g) be responsible for medicine prescription from doctor with support from parents
- h) know who to call to change their appointment (working towards transition; links to medication adherence: Dr. will give you a sheet of paper with tests ordered)

Possible activities include: pictures of key players and roles; kidney twins visiting clinic on poster;

The Parents and Caregivers will be able to:

- a) understand that clinic visits may include time with teen alone
- b) understand it is the parent's responsibility to bring medications to each appointment
- c) encourage and support your teen as they are transitioning

KEY MESSAGES

- 1. To co-ordinate and deliver safe and caring services that promote health and well-being.
- 2. The scope of care is targeted to issues relating to their kidney health. We will also make referral to other health professionals if non-kidney issues are identified.
- 3. Patients and parents should know why they are there before they arrive and be prepared for the visit.
- 4. We endorse the institutional values related to the clinical care mission and vision: Dignity, Care and Respect.
- 5. Friendly and welcoming environment that promotes family centered care patients and families first.
- 6. Patient contact information and demographics should be kept up to date, to foster better communication.
- 7. We deliver service as a clinical care team that includes many health disciplines in an interdisciplinary team environment.
- 8. Patients and parents are an integral part of the team. We invite open communication and decisions are made in collaboration with patients and families.
- 9. Care is co-localized and coordinated to maximize the value of each clinical encounter and minimize patient and caregiver burden.
- 10. Caregivers and patients should feel confident that they understand how the clinic functions and the roles of clinic staff related to their care.
- 11. As patients get older, the focus of the clinic visit will shift in emphasis from the caregivers to the teen.
- 12. Measurements obtained in clinic are done rigorously according to standards that are set by each of the clinical services.
- 13. After the clinic visit, patients and caregivers should be able to confirm the plan that has been developed with their care team, to provide for the medical needs of the patient until the next visit.

TARGETS FOR FACILITATORS TO BE AWARE OF

- 1. Awareness of the specific roles of each team member.
- 2. Patient flow requirements minimizing waiting times at each phase of the clinic visit.
- 3. Identification of measurement standards specific to the clinic, under the direction of the Nurse Clinician and Medical Service Chief.
- 4. Awareness of what the patient/caregivers need to prepare before clinic and bring to clinic (e.g. medication bottles/list).
- 5. Always maintain up to date patient demographics.

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) understand they are coming for kidney check up
- b) name key players by name
- c) have fun

Possible activities include: pictures of key players and roles; kidney twins visiting clinic on poster;

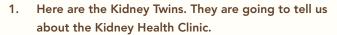
MY APPROACH

- Likely first meeting with the family. How are they?
 Focus on introducing them to clinic, its purpose, the Kidney Health Team. Let them know that, over time, you will work together to create the best kidney health for their child.
- 2. Acknowledge what children do or say.
- 3. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 4. Ask questions to provoke thinking; describe pictures.
- 5. Provide hints to assist children when they are struggling with concepts.
- 6. Offer a variety of choices when children are trying to find the answer.
- 7. While your time is limited, try to give children and family time to think about the material and messages.
- 8. Where is this family at? (Stages of Change)

LEARNING SUPPORTS

Photos of Kidney Health Team with role; pamphlet on clinic;





Options:

Would you like to look at this book with your Mom / Dad?

Would you like your Mom / Dad to read the story?



2. We are happy you are here at the Kidney Health Clinic! We can help.

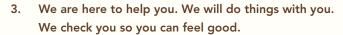
What do you see in the picture?

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.





We will measure how tall you are.

We will put something on your arm and check your blood pressure.

We will touch your tummy and check things in your body.



4. There are some people you should meet!

Cards with photos of Team Member and role description in simple language.

This is Garry. He is a nurse. He will talk to your family and ask you many questions. He is your main contact person with the Kidney Health Clinic.

This is Rhonda. She is a nurse. She might weigh you or see how tall you are or measure your blood pressure.

This is Kerri. She is a clerk. She makes your appointments and might see how tall you are.

Have you seen any of these people? (cards with photos of Kidney Team, their role and a fun fact)

UP NEXT: SCHOOL AGE LEVEL

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) understand and cooperate with having height, weight, blood pressure measured
- b) understand the nurse will check medications
- c) know that urine (pee) test helps nurse and doctor understand how healthy their kidneys are
- d) understand that blood tests help the nurse and doctor understand how healthy their kidneys are
- e) understand that the doctor will talk to them and do a check-up
- f) know that the doctor and nurse will be asking them questions
- g) know that the doctor will give Mom and Dad information on how to keep your kidneys healthy

Possible activities include:

MY APPROACH

- Likely first meeting with the family. How are they?
 Focus on introducing them to clinic, its purpose, the Kidney Health Team. Let them know that, over time, you will work together to create the best kidney health for their child.
- 2. Where is this family at? (Stages of Change)
- 3. Acknowledge what children do or say.
- 4. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 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? Learning supports: photos of Kidney Health Team with role; pamphlet on clinic;



 These are the Kidney Twins and they are going to help you learn about the Kidney Health Clinic.



2. You are here today to get your kidneys checked.

There are many children who come and see us.

There are some questions we will be asking you and some tests we will need to do.

These questions and tests help us make you healthier.



When you come into the Kidney Health Clinic, you will go to the desk.

The Clerk will ask your name and check your information.

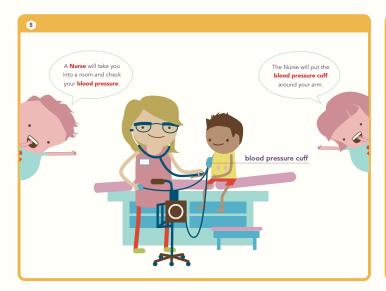


4. You will likely wait for a few minutes in the waiting room. Listen for your name!

When we call your name, we will take you to a new room. Can you tell from the pictures what we are checking?

Yes, we are checking to see how tall you are in the top picture. When we measure your height, or how tall you are, you have to stand still. We also ask you to take your shoes off.

We are checking how much you weigh in the bottom picture. We will ask you to take your shoes off.



When the Kidney Health Team measures your blood pressure, you need to sit quietly and be still. No talking please. Shh... You will feel the cuff around your arm get tight and then get loose.

5. What about this child in the chair?

We are measuring something called Blood Pressure.

Have you had your blood pressure checked before?

6. The nurse's job is to measure your blood pressure.

Your job is to help the nurse by sitting quietly while they check your blood pressure.

Sometimes we have to take your blood pressure 2 or 3 times.

The nurse will put a cuff or a big band around your arm. The band will get tight for a few seconds.





7. What do you think the nurse is asking about?

Learning for parents: It's important to talk about medicines and for the parent to bring medications to clinic.

To child: When we check your blood pressure, what is your job?

To parent and child: When we talk about medicines, your parent's job is to bring your medicines to clinic.

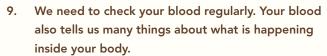
The nurse will ask your Mom and Dad questions about your medicines.

We do different tests to help us understand how healthy your kidneys are.

Have you done a urine or pee test before? This is when you pee in a little cup or into a little hat.

Your urine tells us many things about what is happening with your kidneys.





Before you have a blood test, there is a special cream we can put on your arm. Your parents can put this cream on your arm before you come to the Kidney Health Clinic. It needs time to work.

* Facilitator's Note: If appropriate, discuss numbing cream with parent.

Sometimes you will have your blood test at the clinic close to your home before you see us.

Sometimes you will have your blood tests done here at the Kidney Health Clinic.



10. What do you think the doctor is doing?

The doctor will ask more questions and will check you.

The doctor might need to touch your stomach, your legs, your neck or your back. The doctor might press on your stomach.

The doctor checks your body and asks questions to help us understand how healthy your kidneys are.





11. After the doctors checks you and asks you and your parents some questions, the doctor will talk to you and your parents about some things you need to do for your Kidney Health Care Plan.

Sometimes other people from the Kidney Health Team will come and talk to you too.

Would you like to meet some of the members of your Kidney Health Team?

* Facilitators Note: If appropriate and time allows, show photos of key members of team.

If not appropriate, (child and parents overwhelmed): Next time, I will show you some photos of the Kidney Health Team so you can see some of the people who will be helping you take care of your kidneys.

12. Do you have questions?

Can you tell me why you are at the Kidney Health Clinic?

We will see you next time and talk some more about coming to the Kidney Health Clinic.

Now, I am going to speak to your parents for a few minutes, ok?

Review Parents and Caregiver Resource with Parent or Caregiver.

UP NEXT: ADOLESCENT LEVEL

ADOLESCENT LEARNING



ADOLESCENT LEARNING OBJECTIVES

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

The Adolescent will be able to:

- a) help check in
- b) give a history
- c) talk to the doctor and nurse
- d) understand they can speak privately with any member of their health care team
- e) remember medications
- f) get their next appointment slip
- g) be responsible for medicine prescription from doctor with support from parents
- h) know who to call to change their appointment (working towards transition; links to medication adherence)

Possible activities include: pictures of key players and roles; kidney twins visiting clinic on poster;

MY APPROACH

- Likely first meeting with the family. How are they?
 Focus on introducing them to clinic, its purpose, the Kidney Health Team. Let them know that, over time, you will work together to create the best kidney health for them.
- 2. Where is this family at? (Stages of Change)
- 3. Acknowledge what the adolescents say and do.
- 4. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 5. Ask questions to provoke thinking; describe pictures.
- 6. Guide, do not dictate. Youth want info so they can make their own decisions.
- 7. Be patient. Don't be discouraged if your first offers of support are turned down.
- 8. Give opportunities to use strategic thinking, reasoning and problem solving.
- 9. Let them do some evaluation and monitoring of their understanding.
- 10. 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? Learning supports: photos of Kidney Health Team with role; pamphlet on clinic;

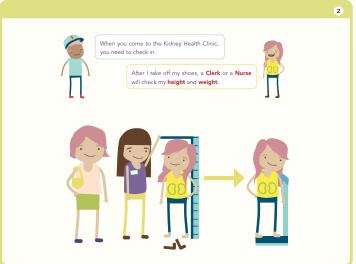


 Today we are going to talk about your Kidney Health Clinic. There is a team of people here to help you be as healthy as you can be. This is the Kidney Health Team.

There are a few things that happen at almost every clinic appointment.

Let's find out what these steps are and answer questions you might have.

* Facilitator's Note: Give adolescent time to review material themselves.



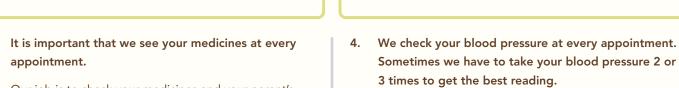
2. When you come to the Kidney Health Clinic, you check in at the desk.

The Clerk will check your information and then you will wait in the waiting area.

Someone will call your name. You will come to the room where we check your weight and height.

For both these tests, we will ask you to take off your shoes.





Have you had your blood pressure taken before?

4

The Nurse checks my blood pressure. The Nurse puts the **cuff** around my arm. The cuff gets tight and then loose again.

It's important to sit quietly during

Your job is to sit quietly while we take your blood pressure.

Our job is to check your medicines and your parent's job is to bring the medicines to the appointments.



 We have to get lots of information from you when you come to clinic. All this information helps us help you look after your kidneys.

The nurse and doctor will ask questions about medicines, eating and activity.

Ask your doctor if there are signs or symptoms you should be watching for.

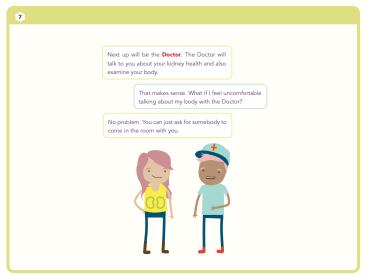


A urine test tells us a lot about what is happening with your kidneys.

Have you done a urine test before?

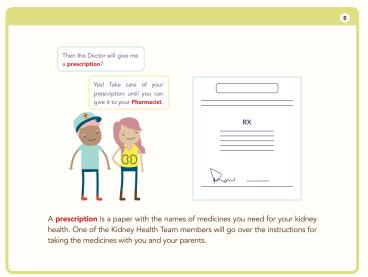
We also test your blood to tell us what is happening with your kidneys. Sometimes you might have a blood test before you come to clinic or we might do blood and urine tests in between clinic appointments.

You might go see your local health centre to have these tests done and the information is sent to your Kidney Health Team – but you might not see any of them.



 The doctor will see you next. The doctor will talk to you about your kidney health and examine you.

Some people feel uncomfortable being examined and if you want someone there with you, that's fine.



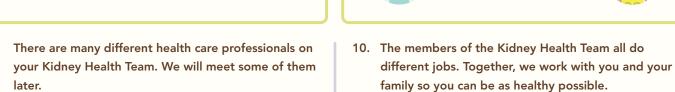
8. The doctor and / or nurse will give you a prescription and review the prescription with you and your parents.

A prescription gives the names of medicines you need to take and detailed instructions.

Make sure you talk to the pharmacist about the instructions when you pick up the medicines.

It is always best to take the medicines how the doctor prescribes.





you, your family and your friends.

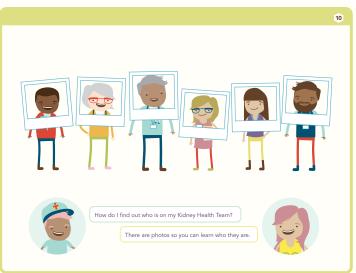
Here are the main members of your team.

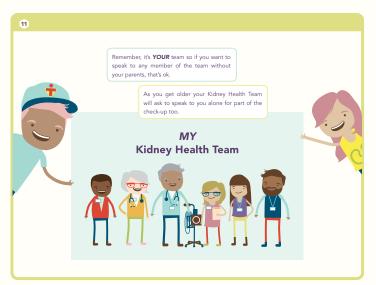
(Show Photos)

Do you have any questions about The Kidney Health Clinic?

We all have to work together: the Kidney Health Team,

Often at your appointments, a few of them will want to talk to you.





11. Sometimes, especially as you get older, the Kidney Health Team will want to speak to you alone. This is to help prepare for you becoming an adult and looking after your own kidney health.

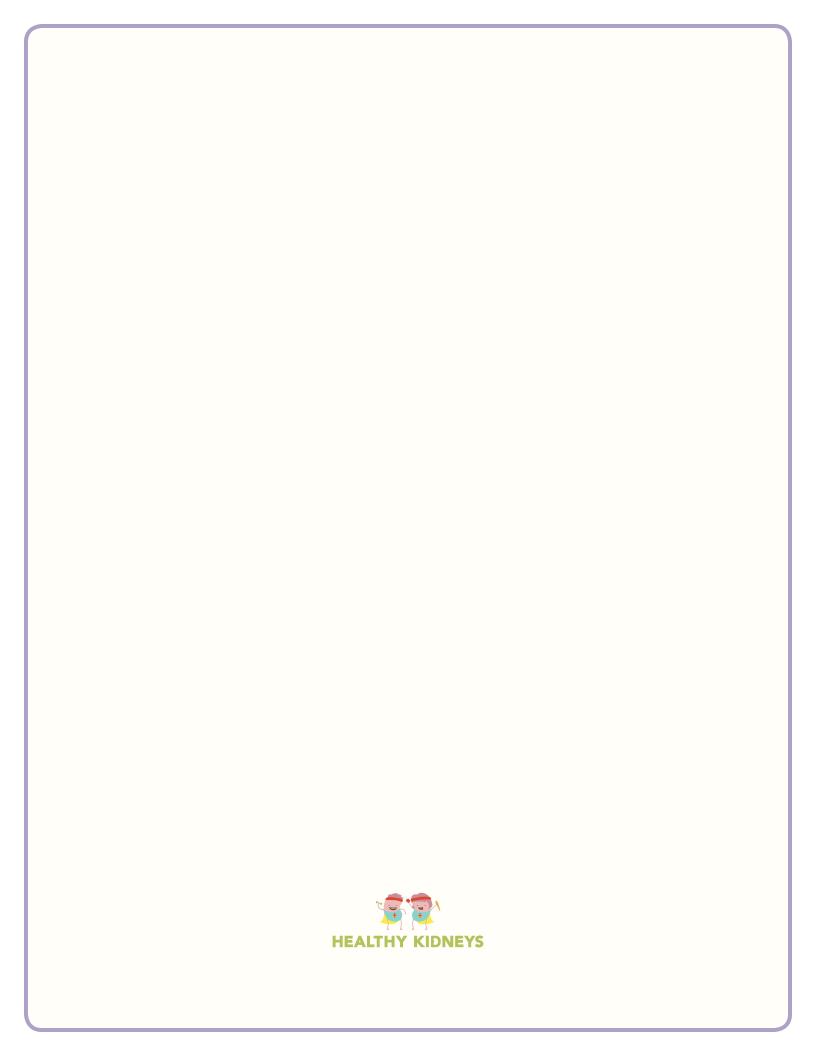
You might want to speak to the Kidney Health Team members on your own too. That's fine. We can ask your Mom or Dad to wait outside while we talk to you by yourself.



12. Your Kidney Health Clinic visit ends with setting up your next appointment.

If you need to change your appointment, you can call \dots

Now I'm going to spend a few minutes reviewing some information with your parents.











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