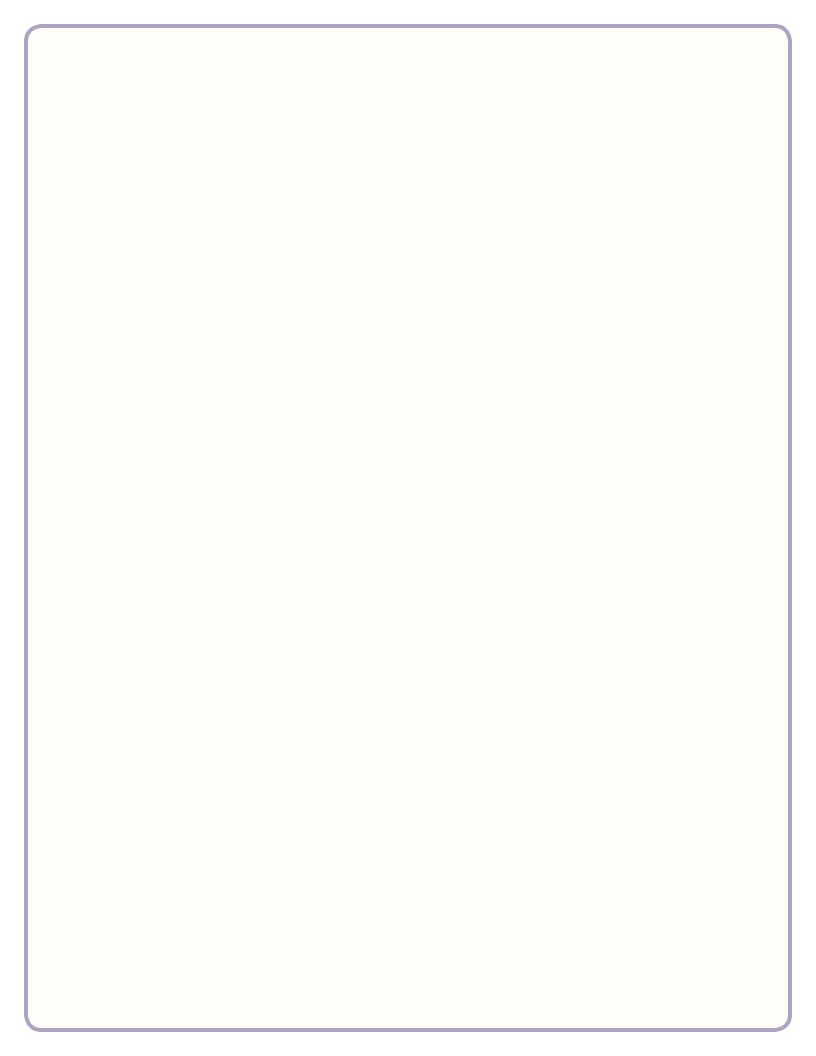


# **MY COPING RESOURCES**

**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







### 15. GLOBAL LEARNING OBJECTIVES

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

- identify how chronic kidney disease affects me
- focus on how to adapt to chronic kidney disease
- know "it's ok to ask" (no question is dumb)
- know that how they are feeling is normal

This module is an opportunity to provide permission and encouragement to talk about how the child is feeling and acknowledge that not everything can be detected by a blood or urine test.

### 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) name that they have a problem with their kidneys
- b) recognize that they have differences and similarities with other children
- c) recognize that everyone is unique

Possible activities include: exploring other people they know who have a problem with their lungs, walking, etc

## The School Age Child will be able to:

- a) identify who they would go to for help in their community / environment
- b) identify two resources they could access easily with their parent's help
- c) identify that they have a problem with their kidneys
- d) know that other children have kidney disease
- e) identify that there are some things we all do to stay healthy (brush our teeth, sleep, take vitamins, etc)
- f) talk about special things other children have to do to stay healthy (take inhalers, not touch / eat peanuts, etc)
- g) practice role-playing with a caregiver to talk about their kidney disease and its management

**Possible activities include:** Kidney Camp; peers for supports; dialysis video: <a href="http://www.youtube.com/">http://www.youtube.com/</a> watch?v=vfNKvPTc 6E

### The Adolescent will be able to:

- a) recognize and describe how kidney disease impacts their life
- b) identify that there are some things that we all do to stay healthy
- c) talk about different things other people have to do to stay healthy (take inhalers, not touch peanuts, take vitamins, etc)
- d) see stars / celebrities with kidney transplants or serious illnesses
- e) understand adaptation will take place over time

Possible activities include: dialysis video: http://www.youtube.com/watch?v=yfNKyPTc\_6E

### The Parents and Caregivers will be able to:

- a) understand that adaptation will take place over time
- b) communicate with their child regarding chronic disease and the impact it has on child
- c) support their child's feelings

### **KEY MESSAGES**

- 1. Kidney disease is a life-long chronic disease.
- 2. We stress the importance of living with kidney disease, rather than being afflicted with it. The goal in helping children is that over time, adaptations to, and living well with, kidney disease becomes integrated as part of life.
- 3. Adaptation to kidney disease takes time for the child and family.
- 4. We need to recognize the different stages of emotional development (concrete vs. abstract thinking), and tailor coping strategies to the child's developmental stage.
- Children will have emotional responses that are "unseen", in addition to the physical signs and symptoms reported to the team. It is important to probe for these at each clinical encounter to uncover them and address them.
- 6. Part of how kids feel emotionally is related to physical aspects of their well-being, such as fatigue, nausea, pain, etc.
- 7. Some children will experience post-traumatic-type of stress after major life-threatening events.
- 8. Potentially stressful changes are common in the course of living with kidney disease. That reality should be discussed early in the course of disease, acknowledging the associated stress it causes, and normalize those responses.
- 9. Different events in the course of living with disease are very distressing (e.g. starting dialysis), and children will sometimes experience a grief response, and will progress through coping with grief stages at different rates even within the family.
- 10. Feeling different is common and may be perceived negatively by some children, especially during adolescence, and should be acknowledged in discussing coping strategies. This can also manifest in alterations in body image and behaviour.
- 11. Many children have kidney disease of different kinds. Though we talk about the fact that kidney disease is rare in children, our program takes care of many kids with similar issues. We have the resources to support them.
- 12. It is important to recognize that children may struggle with adversity and have difficulty moving beyond initial denial toward acceptance. Motivational interviewing techniques will be useful to identify readiness for change.
- 13. Many people on the team have expertise and play a role to support children with kidney disease including social workers, nurses, doctors, child life therapists, psychiatry and psychology services, pharmacist, dietitian, spiritual care workers, and others.
- 14. We will also identify community supports to help with coping, including the primary physician, nursing station, social workers, child and family services, mental health referral services, and others.
- 15. We believe in family-centered care. That means that we will support the child in the context of the needs of the whole family.
- 16. We will include the family as part of the support team for the child, meaning that we will develop coping strategies together with the family- in the context of their living situation and in ways that work for them.

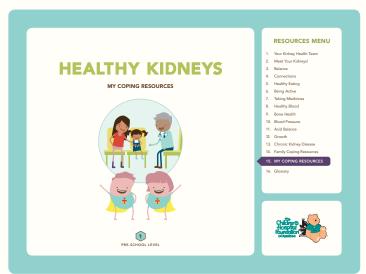
### **KEY MESSAGES CONTINUED...**

- 17. Parents are a key resource in assisting children with their coping. It is important to first assess the parent's response to new information and address their coping needs. If parents have not achieved some adaptation to the information, they may not be able to support their child in receiving the information.
- 18. Coping strategies that can be discussed will include: encouraging children to ask for help (it's OK to ask); crying and expressing emotions in a safe environment; writing down experiences and feelings about them; encouraging other outlets to express feeling (art, play).
- 19. Be aware of signs of unhealthy or maladapted coping, such as: non-adherence to treatment, bullying behaviour at school, aggressive play with siblings or peers, isolation or disassociation from friends or families, oppositional behaviour, appearance of high-risk adolescent behaviours (drinking, drug use, self-harm, hypersexuality, risk-taking). In these cases, it is important to seek help from trained mental health or support professionals.
- 20. It's also important to identify supports outside of the family, including friends and other important adults this needs to be balanced with the desire of families to be private about their health issues.
- 21. Part of coping is to normalize some aspects of care that may happen related to kidney disease care (e.g. G-tubes, catheters, scars).
- 22. Adolescence is a unique and vulnerable time. We will pay special attention to supporting adolescents as they deal with emotional challenges related to their disease that are in addition to the developmental tasks that are normally faced by their peers.

### TARGETS TO BE AWARE OF:

- 1. Psychometric testing may be used to assess cognitive ability and adaptive capacity
- 2. There are defined stages of grief (e.g. Kubler-Ross)
- 3. Signs and symptoms of post-traumatic stress
- 4. HEADSS assessment for adolescent risk behaviours
- 5. Emotional development stages of children and adolescents
- 6. Transition tool for assessment provides measurement of supports and adjustment

### 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) name that they have a problem with their kidneys
- b) recognize that they have differences and similarities with other children
- c) recognize that everyone is unique

**Possible activities include:** exploring other people they know who have a problem with their lungs, walking, etc

### **MY APPROACH**

- 1. Review Motivational Interviewing.
- 2. Assess where family is at re: Stages of Change
- Remind family that the Kidney Health Team and the child and family are on the same team. Acknowledge patient's and family's feelings and experiences. Recognize it takes time to adjust to and learn to live with a chronic illness.
- 4. 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?

### **SOCIAL WORK SUGGESTIONS**

- It is important to show empathy and good listening skills. You can convey these by understanding and simple signs of warmth such as providing a warm / quiet area to talk in and ensuring kleenex is nearby.
   Be prepared to take time. Ensure that your body language shows caring and concern.
- 2. Ask open-ended questions about the family lifestyle so you can have a better understanding of and develop perspective on how the family operates or lives. Asking questions about leisure activities or how the family spends time together will help you develop understanding of the family system, its roles and relationships. The ecomap can be helpful if the family is large and complicated.
- 3. Encourage the family/child to express strengths and try to build upon these strengths. Create discussions that will encourage the family to ask questions and see themselves as the leader which will hopefully help empower them to develop their own healthy coping strategies.





### 1. What do you see in this picture?

Lots of different children.

How are they different from each other?

- bigger / smaller
- look different
- etc

How are they same as each other?

- they like to play
- maybe they have brothers and sisters
- they go to school
- they eat
- they like their pet
- etc

Even though we are different in some ways, there are many things that are the same.

# 2. 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?





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

4. You come here to have your kidneys checked.

Remember, every one has things that are different and some things that are the same.

Do you know children who have a puffer? Do you know children who have trouble moving? Do you know other people who have trouble talking?

It's ok to be different. There are lots of things that are the same as other kids too.

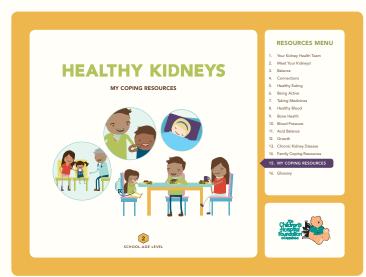




When you come to Kidney Clinic, you can ask us anything. You can tell us how you are feeling and what you are thinking about. We need to know how you are feeling. Sometimes you might want to just say "ok" but you can also tell us more.

There are lots of people at Kidney Clinic for you to talk to. We are all here to help.

### **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) identify who they would go to for help in their community / environment
- b) identify two resources they could access easily with their parent's help
- c) identify that they have a problem with their kidneys
- d) know that other children have kidney disease
- e) identify that there are some things we all do to stay healthy (brush our teeth, sleep, take vitamins, etc)
- f) talk about special things other children have to do to stay healthy (take inhalers, not touch / eat peanuts, etc)
- g) practice role-playing with a caregiver to talk about their kidney disease and its management

**Possible activities include:** Kidney Camp; peers for supports; dialysis video: http://www.youtube.com/watch?v=yfNKyPTc\_6E

### **MY APPROACH**

- 1. Review Motivational Interviewing.
- 2. Assess where family is at re: Stages of Change
- Remind family that the Kidney Health Team, parents and child work together to create the best kidney health for the child.
- 4. Acknowledge patient's and family's feelings and experiences. Recognize it takes time to adjust to and learn to live with a chronic illness.
- 5. Provide information directly giving children facts, labels and other information.
- 6. Ask questions to provoke thinking; ask children to describe pictures.
- Offer a variety of choices when children are trying to find the answer
- 8. Provide hints to assist children when they are struggling with concepts.
- 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?

### **SOCIAL WORK SUGGESTIONS**

- It is important to show empathy and good listening skills. You can convey these by understanding and simple signs of warmth such as providing a warm / quiet area to talk in and ensuring kleenex is nearby.
   Be prepared to take time. Ensure that your body language shows caring and concern.
- 2. Ask open-ended questions about the family lifestyle so you can have a better understanding of and develop perspective on how the family operates or lives. Asking questions about leisure activities or how the family spends time together will help you develop understanding of the family system, its roles and relationships. The ecomap can be helpful if the family is large and complicated.
- 3. Encourage the family/child to express strengths and try to build upon these strengths. Create discussions that will encourage the family to ask questions and see themselves as the leader which will hopefully help empower them to develop their own healthy coping strategies.

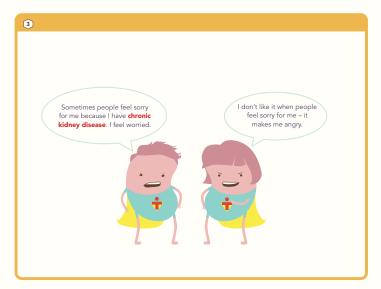


1. Nice to see you again. Do you know why you come to see us?

Yes, you are here to get your kidneys checked.



We check your kidneys at the Kidney Health Clinic.
 There are many children who come and see us to have their kidneys checked.





### 3. Does this ever happen to you?

How does it make you feel when people feel sorry for you because you have kidney disease?

4. Sometimes it takes people time to understand that you are still you.

Your family can help with this. You still have to go to bed and do your homework and clean your room, right? You're still you!





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

Sometimes you might want to just say "ok" or "fine" but you can also tell us more.

Sometimes we might ask you if you have an upset tummy, if you feel tired, if you feel sad, or have a headache. Or we might ask if you are itchy. Sometimes, it's even harder to talk about feelings.

Can we try something? Would you like to try being the nurse or doctor? I will be the person who has to do something special to keep my kidneys healthy. What questions would you want to ask me?

Role play with the nurse or role play with the puppet.

Switch roles.

6. Look at all these faces! They all look like they are feeling differently. How do you think this one (point to one) is feeling?

If appropriate, ask child which face looks like how they are feeling about chronic kidney disease.





7. You have problems with your kidneys. There are some special things you need to do to help your kidneys stay healthy, right?

But did you know that other people have things they have to do to stay healthy too?

8. What are some things we all do to keep healthy?

10





 Many people have special things they need to do to stay healthy. Sometimes we see these things and sometimes we don't see them.

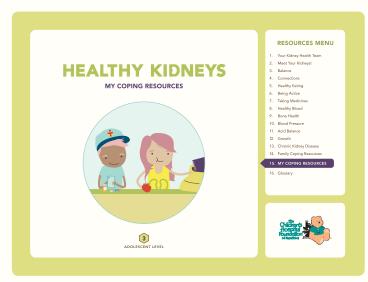
Sometimes it might feel like you are the only one who has to do special things, but you're not.

Do you know some people who have to do special things to stay healthy?

10. It takes time to learn what you need to do to be healthy. Most of the time, it also takes help from other people. Your Kidney Health Team is here to help as much as we can.

What kinds of things do you do to keep healthy?

### **ADOLESCENT LEARNING**



### ADOLESCENT LEARNING OBJECTIVES

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

### The Adolescent will be able to:

- a) recognize and describe how kidney disease impacts their life
- b) identify that there are some things that we all do to stay healthy
- c) talk about different things other people have to do to stay healthy (take inhalers, not touch peanuts, take vitamins, etc)
- d) see stars / celebrities with kidney transplants or serious illnesses
- e) understand adaptation will take place over time

Possible activities include: dialysis video: http://www.youtube.com/watch?v=yfNKyPTc\_6E

### MY APPROACH

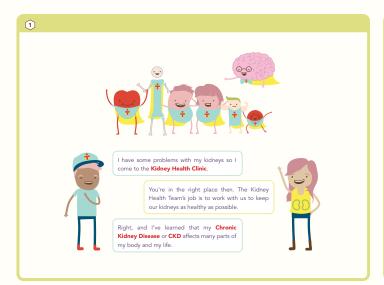
- 1. Review Motivational Interviewing.
- 2. Assess where family is at re: Stages of Change
- Remind family that the Kidney Health Team, parents and child work together to create the best kidney health for the child.
- 4. Acknowledge patient's and family's feelings and experiences. Recognize it takes time to adjust to and learn to live with a chronic illness.
- Acknowledge what the adolescents say and do.
   Model attitudes, ways of approaching problems and
   behaviours (Don't tell)
- 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.

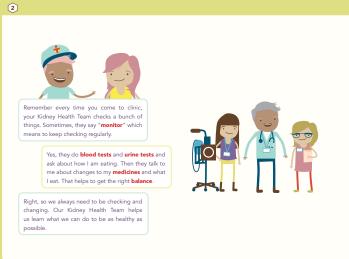
### **LEARNING SUPPORTS**

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

### **SOCIAL WORK SUGGESTIONS:**

- It is important to show empathy and good listening skills. You can convey these by understanding and simple signs of warmth such as providing a warm / quiet area to talk in and ensuring kleenex is nearby.
   Be prepared to take time. Ensure that your body language shows caring and concern.
- 2. Ask open-ended questions about the family lifestyle so you can have a better understanding of and develop perspective on how the family operates or lives. Asking questions about leisure activities or how the family spends time together will help you develop understanding of the family system, its roles and relationships. The ecomap can be helpful if the family is large and complicated.
- 3. Encourage the family/child to express strengths and try to build upon these strengths. Create discussions that will encourage the family to ask questions and see themselves as the leader which will hopefully help empower them to develop their own healthy coping strategies.





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.

 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 changes 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.

(4)





You're right, we all have things we need to do to stay healthy. Some days it's easy to

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.

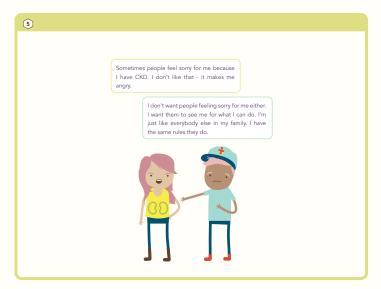
What are some things you do every day to stay as healthy as you can?

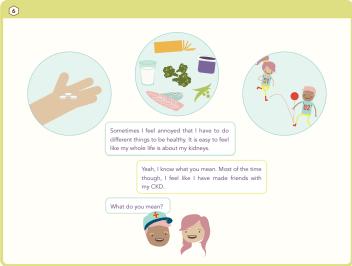
 To live best with your chronic disease, you have choices to make about taking medicines, eating and activity every day.

There is a lot to learn about living well with your disease.

What do you think about that?

There are lots of people who have to do different things every day to stay healthy.





### 5. Does this ever happen to you?

How does it make you feel when people feel sorry for you because you have kidney disease?

6. How do you feel about your disease? Having lots of different feelings is normal. It's important to be able to talk about them with someone.

Have you ever felt like your whole life is about your kidneys and people don't see you?

What do you think about this idea of "making friends" with your kidney disease?



# Yeah, my teacher uses a puffer for his asthma and my neighbour is on a special diet for diabetes. There's lots of famous people living with health issues too. Do you know any?

### 7. What do you think of this?

Do you think you can figure out how to "make friends" with your kidney disease?

8. It takes time and patience to learn to live with a chronic disease.

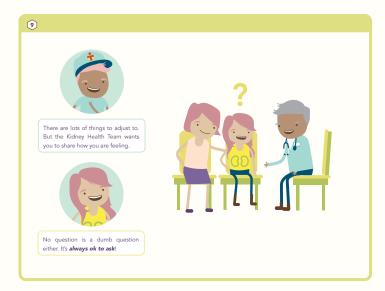
If you have been living with a chronic disease all your life, it's just part of life. If you get a disease a bit later, sometimes it's harder to adjust.

Almost everyone has special things they have to do to stay healthy.

Our feelings change over time. How have you been feeling about your kidney disease lately?

Could google with adolescent "famous people with kidney disease"

Famouspeoplearehuman.com (all sorts of diseases)





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

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

Sometimes, it's even harder to talk about feelings.

Can we try something? If I was the patient and you were the doctor or nurse, what kinds of questions would you ask me?

Role play. Switch roles.

# 10. Your feelings will change over time about your disease and how you live with it.

The most important thing is to keep adapting and to keep getting help when you need it.

\* Facilitator's Note: May want to suggest Kidney
Connect <a href="http://kidney.ning.com">http://kidney.ning.com</a> (online) or by phone:
1-866-390-7337 (PEER)

### KidsHelpPhone.ca

1800-668-6868

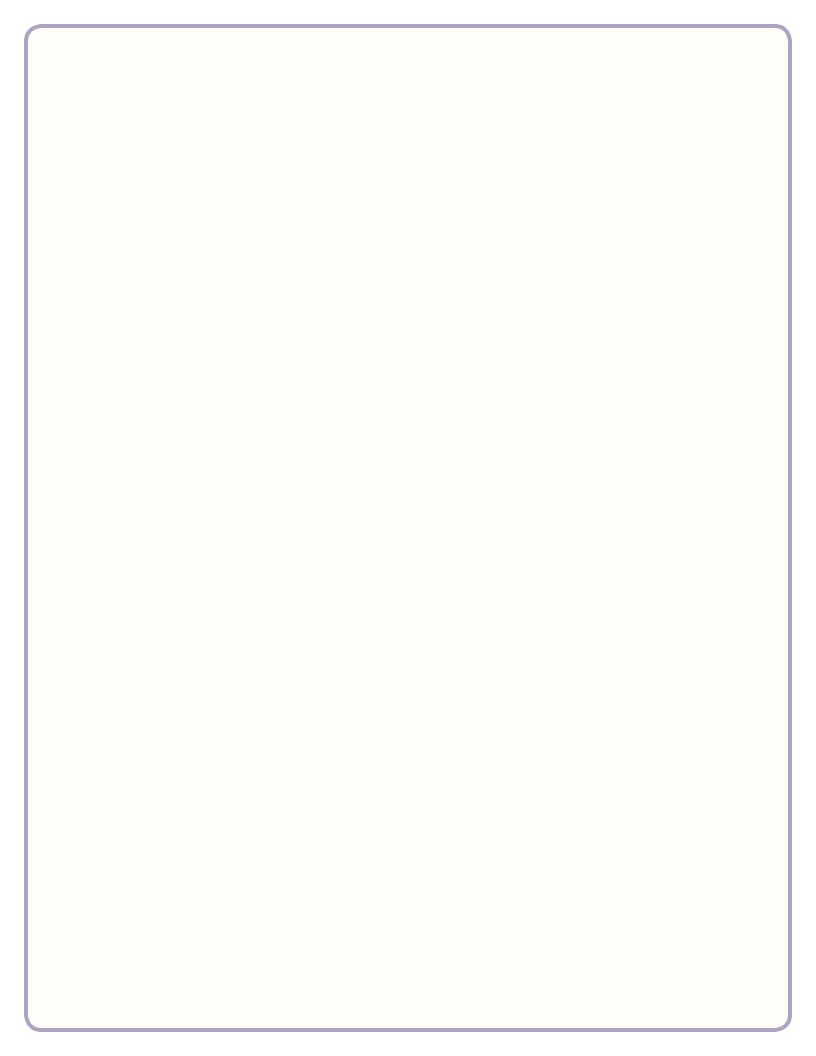
Teens can also post questions

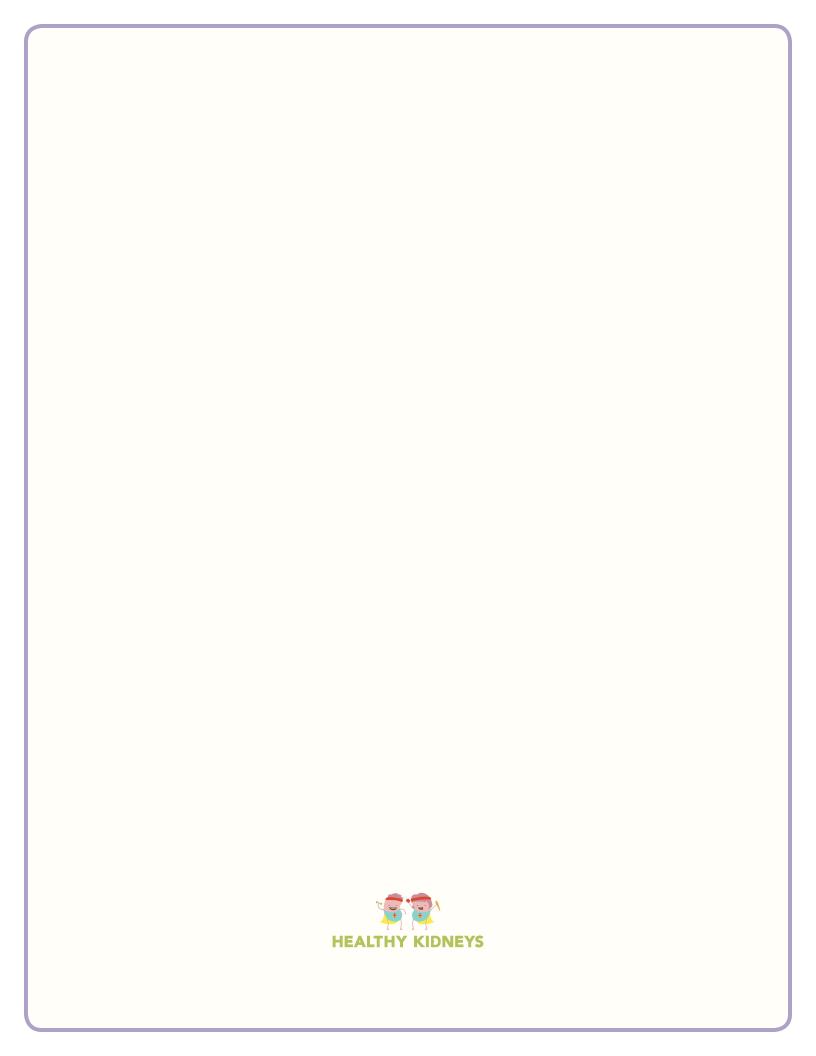
http://www.kidshelpphone.ca/Teens/AskUsOnline.

aspx



### **ADDITIONAL NOTES**













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