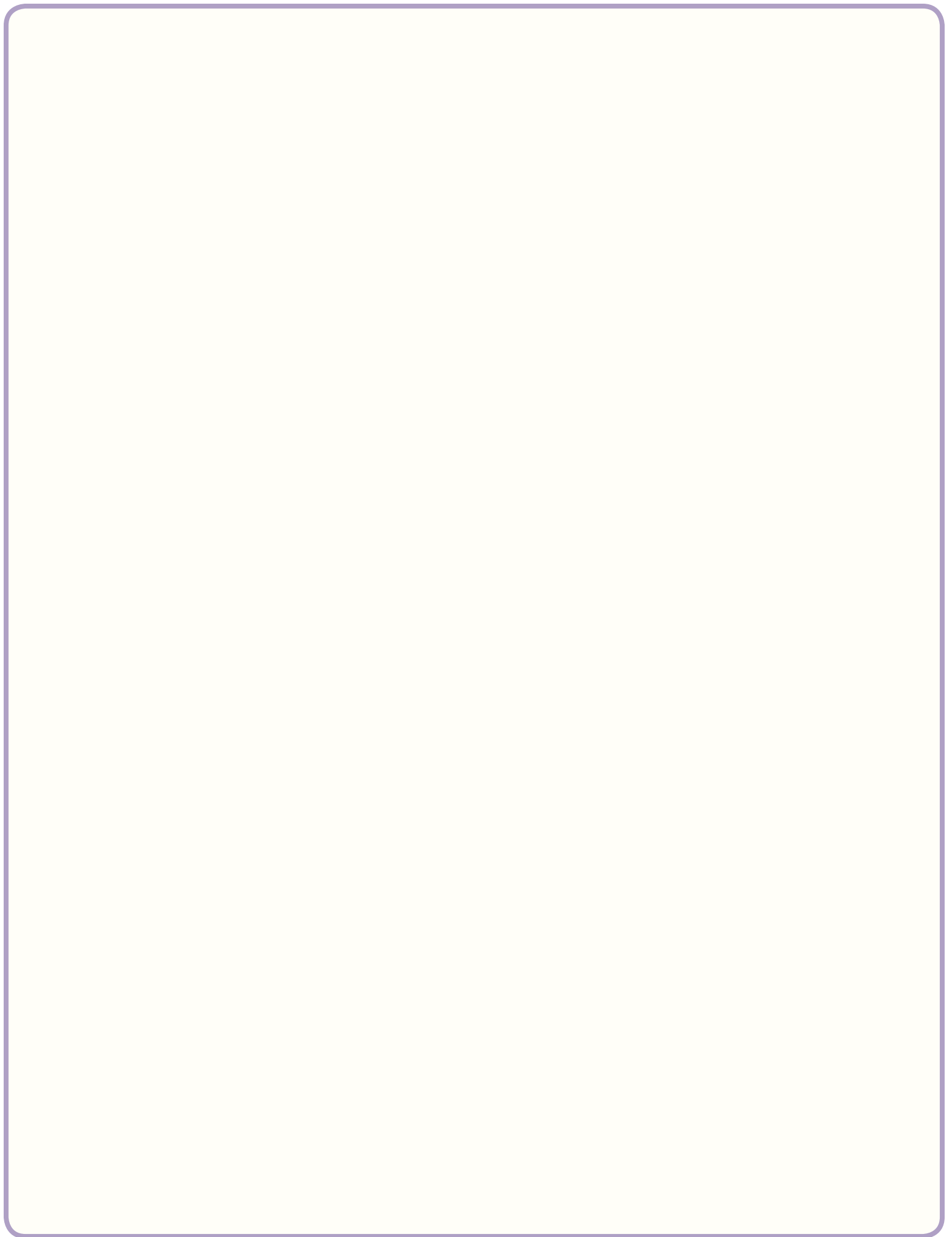




FAMILY COPING RESOURCES

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

PRE-SCHOOL LEVEL



SCHOOL AGE LEVEL



ADOLESCENT LEVEL



14. GLOBAL LEARNING OBJECTIVES

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

- know what resources to assist with coping are available locally
- understand how to access those resources
- know that there is loss and grief associated with diagnosis of chronic illness

This module is an invitation, to validate and affirm the experience and feelings of loss and grief. This diagnosis is a life-altering event, associated with all these feelings in you, your family and your child.

Supports: endorsed list of resources: KFOC-MB Branch; Living with KD book; Kidshealth.org;

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 who is safe to access in their community / environment
- b) report how they are feeling to that person
- c) know that if you are sick or scared, your parents can help (routine)

Possible activities include:

The Adolescent 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

Possible activities include:

The School Age Child will be able to:

- a) recognize that when I'm sick, it impacts my brothers and sisters and my family (they looked sad after they met with the Kidney Health Team)
- b) look at faces of family members and consider how they might be feeling
- c) know that there is loss and grief associated with disease
- d) know CKD is part of my life, not my whole life
- e) know we are all part of a team
- f) know that everybody in my family does different things to stay healthy
- g) know that managing my kidney disease involves everyone in my family

Possible activities include:

The Parents and Caregivers will:

- a) teach children who is safe to go to and report if they are feeling sick at daycare / preschool / friend's house / school etc
- b) supervise children accessing information
- c) understand some unique aspects to parenting a child with chronic illness
- d) appreciate the benefits of routine to cope with chronic disease
- e) know where to go for help for their coping
- f) identify the role of social work; parenting resources (Positive Parenting Program)

KEY MESSAGES

1. Living with Kidney Disease

- o Kidney disease is a life-long chronic disease and can impact the entire family.
- o We stress the importance of living with kidney disease, rather than being afflicted with it. The goal in helping families with a child with KD is that over time, adaptations to and living well with kidney disease becomes integrated as part of life.
- o Adaptation to kidney disease takes time for the family and the child.
- o Different access to resources is a reality, depending on geography- remote vs. rural vs. urban. Also impacted by systems that are supporting access to medical care eg FNHI or EIA.
- o 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 families with different types of kidney disease.

2. Family Centred Care

- o We believe in family-centered care. That means that we will support the child in the context of the needs of the whole family while recognizing that differing cultures/families have differing needs and expectations.
- o The focus on social and emotional health should target the home environment as a whole, rather than tailoring elements of the home specifically for the child with kidney disease.
- o Assessment and awareness of caregiver resiliency and coping is part of supporting the child, as caregivers may themselves need attention and personal support.
- o 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.
- o Family structures vary and the resiliency of different family structures needs to be considered in designing supports.
- o Sibling responses to a child in the family may be underappreciated and should be addressed as a specific task in helping with family coping. Siblings should be screened for signs of emotional distress, and services made available to them as needed.
- o Building a strong relationship between the team and family will facilitate open and honest communication regarding their coping and emotional needs.
- o Parenting styles will differ, which may influence the capacity to support their child and other siblings at times of stress. Supports for positive parenting are available and should be offered early.
- o Family members may have emotional responses that are "unseen". It is important to probe for these at each clinical encounter to uncover them and address them.
- o It is important to recognize that families may struggle with adversity and have difficulty moving beyond initial denial toward acceptance. Motivational interviewing techniques will be useful to identify readiness for change.
- o There is a high risk of marital and relationship breakdown, associated with challenges in coping with new demands from the child's chronic disease. This needs to be identified early on and continually reassessed, to proactively provide relationship support for the caregivers.
- o 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.

KEY MESSAGES CONTINUED...

2. Family Centred Care Continued...

- o Families need to recognize the different stages of emotional development (concrete vs. abstract thinking) of the patient, and the effect that may have on the family, and help the family adapt to this while tailoring coping strategies to the child's developmental stage.
- o It is important for families to understand that part of how kids feel emotionally is related to physical aspects of their well-being, such as fatigue, nausea, pain, etc.
- o Some families (including siblings or other family members) may experience post-traumatic type of stress when and if their child experiences major life-threatening events related to their child's kidney.

3. Loss and Grief

- o Caregivers are likely to experience a sense of great loss with regard to the future at the diagnosis of chronic kidney disease. They may experience grief responses associated with that loss and will need support through them.
- o Grief responses are waxing / waning and are not a single event.
- o Different events in the course of living with disease are very distressing (e.g. starting dialysis), and family members may sometimes experience a grief response, and will progress through coping with grief stages at different rates even within the same family unit.
- o There are potentially multiple events each of which may be associated with a loss and grief response to events in the course of life of their child with chronic kidney disease.
- o Caregivers need to look at the responses of other children in family etc in coping with their CKD.

4. Stress

- o 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.
- o 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. Family members may also experience these feelings; this should be acknowledged in discussing coping strategies.
- o Many people on the team have expertise and play a role to support children with kidney disease and their families including social workers, nurses, doctors, child life therapists, psychiatry and psychology services, pharmacist, dietitian, spiritual care workers, and others.
- o We will also identify community supports to help families with coping, including the primary physician, nursing station, social workers, child and family services, mental health referral services, and others.
- o Assessment of additional stressors beyond the child and kidney disease include: Financial burden, geographical dislocation, relocation of home/living arrangements, navigating the big city, safety, interruption of work, interruption of school for child and siblings, loss of social support network.
- o Families may suffer a perceived loss of independence, from needs for financial assistance.

KEY MESSAGES CONTINUED...

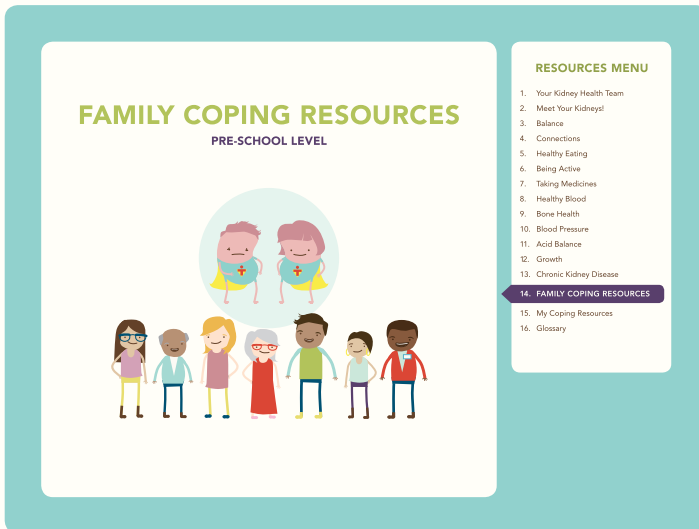
5. Coping

- o Coping strategies that can be discussed will include: encouraging families 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) amongst others.
- o Family structures vary and the resiliency of different family structures needs to be considered in designing supports. Keeping and reinforcing established routines is an important activity in coping with chronic illness. Disorder in one area of your life – chronic disease – can feel less stressful by ensuring order in other areas of life.
- o Be aware of signs of unhealthy or maladapted coping, such as: non-adherence to treatment, isolation or disassociation from friends or extended family, oppositional behaviour, appearance of high-risk behaviours (drinking, drug use, self-harm, hyper- sexuality, risk-taking). In these cases, it is important to seek help from trained mental health or support professionals.
- o It's also important to identify supports outside of the family, including friends and other important adults; the identification of these supports needs to be balanced with the desire of families to be private about their health issues.
- o Part of coping is to normalize some aspects of care that may happen related to kidney disease care (e.g. G-tubes, catheters, scars).
- o Adolescence is a unique and vulnerable time. We will pay special attention to supporting families and 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 FOR FACILITATORS 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) identify who is safe to access in their community / environment
- b) report how they are feeling to that person
- c) know that if you are sick or scared, your parents can help (routine)

Possible activities include:

MY APPROACH

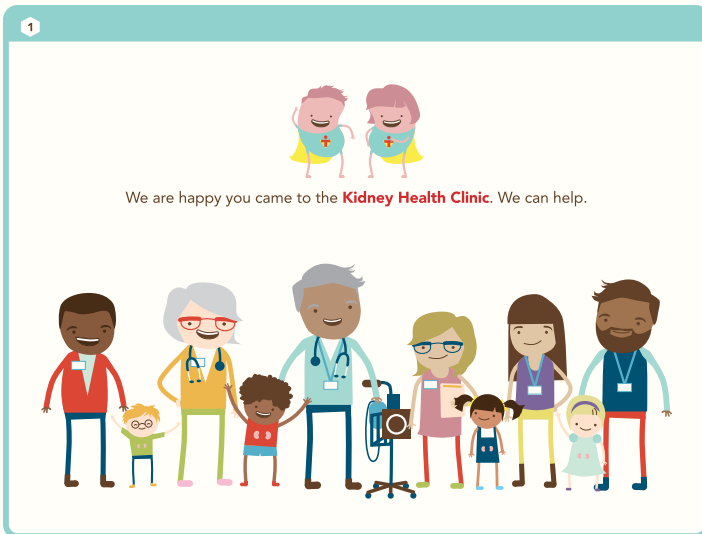
1. Review Motivational Interviewing.
2. Assess where family is at re: Stages of Change.
3. Remind family that the Kidney Health Team and the child and family are on the same team. Understand that realities regarding resources will be greatly influenced by geographic location.
4. Acknowledge patient's and family's feelings and experiences. Recognize it takes time to adjust to and learn to live with a chronic illness.
5. Acknowledge what children do or say.
6. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
7. Ask questions to provoke thinking; describe pictures.
8. Provide hints to assist children when they are struggling with concepts.
9. Offer a variety of choices when children are trying to find the answer.
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?

SOCIAL WORK SUGGESTIONS

1. 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.
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. 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.

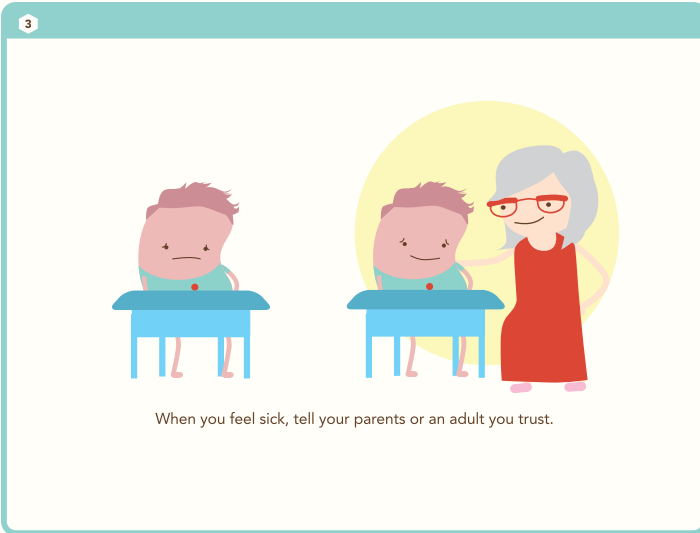
Do you see other children? Yes, many other children come here too. We are here to help keep your kidneys healthy.



2. When you have kidney disease, it is important to tell your parents or an adult you trust if you feel sick. Have you done that before? Who do you tell?

- parents
- teachers
- friend's parents
- an adult
- neighbour
- grandparents
- aunts / uncles
- older sibling

* **Facilitators Note:** Use this opportunity to discuss with parents who they would like their child to report a problem to in various settings. Make sure it is clear to the child who they should talk to.



3. Sometimes, you don't know if you feel sick but something feels funny. You should tell an adult.

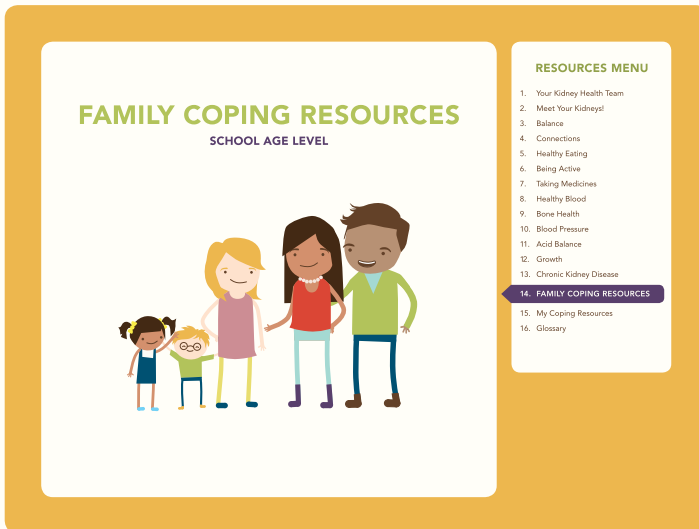
- * **Facilitator's Note:** For parents, it is important that you tell some adults in your child's life that your child has kidney disease. These adults have been identified as someone safe for your child to report to. You should talk with the adult about what to do if your child tells them they don't feel right.

If you feel funny, what can you do?

Tell an adult.

- * **Facilitator's Note:** Remind parent that sometimes children have a hard time expressing how they are feeling and might not have the words to say it.

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) recognize that when I'm sick, it impacts my brothers and sisters and my family (they looked sad after they met with the Kidney Health Team)
- b) look at faces of family members and consider how they might be feeling
- c) know that there is loss and grief associated with disease
- d) know CKD is part of my life, not my whole life
- e) know we are all part of a team
- f) know that everybody in my family does different things to stay healthy
- g) know that managing my kidney disease involves everyone in my family

Possible activities include:

MY APPROACH

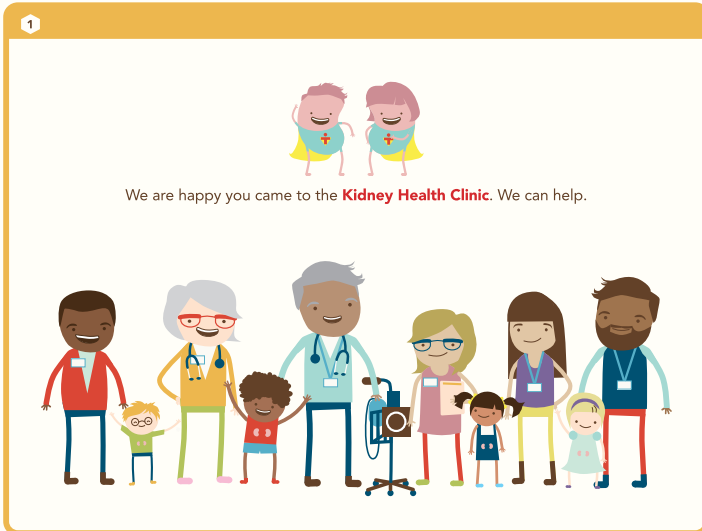
1. Review Motivational Interviewing.
2. Assess where family is at re: Stages of Change.
3. Remind family that the Kidney Health Team, parents and child work together to create the best kidney health for the child.
4. Remind family that the Kidney Health Team and the child and family are on the same team.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

SOCIAL WORK SUGGESTIONS

1. 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.
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. 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.

Do you remember why you come to Kidney Health Clinic?



2. When you have kidney disease, it is important to tell your parents or an adult you trust if you feel sick. Have you done that before? Who do you tell?

- parents
- teachers
- friend's parents
- an adult
- neighbour
- grandparents
- aunts / uncles
- older sibling

* **Facilitator Note:** Emphasize with child that it is important to talk to parents / trusted adult with how they feel both physically and emotionally.

Use this opportunity to discuss with parents who they would like their child to report a problem to in various settings. Make sure it is clear to the child who they should talk to.



3. How do you think this person is feeling?

Do you ever feel this way?

Do you see the people around you feeling like these pictures sometimes?

Sometimes, you don't know if you feel sick but something doesn't feel so good.

Do you feel ...

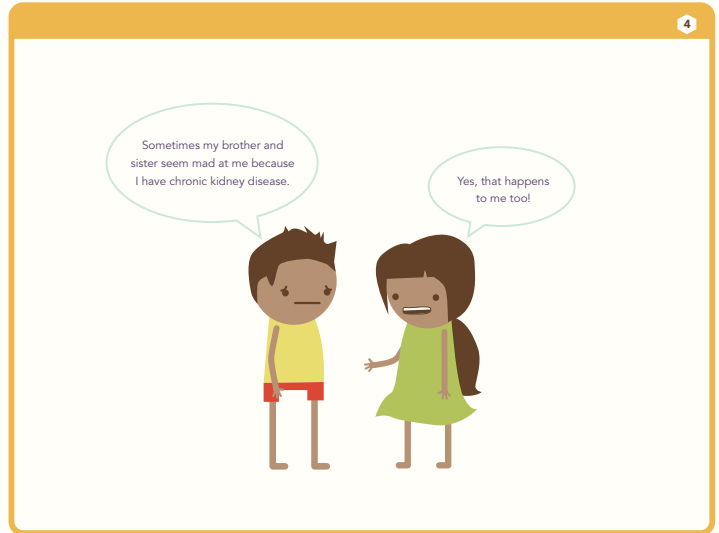
- worried
- scared
- uncomfortable
- nervous
- happy

What do you think you can do?

Tell an adult.

* **Facilitator's Note:** For parents, it is important that you tell some adults in your child's life that they have kidney disease and they have been identified as someone safe for your child to report to. You should talk with the adult about what to do if your child tells them they don't feel right.

Today I Feel Silly, written by Jamie Lee Curtis might be a useful resource.



4. There are lots of feelings when people have a disease. Sometimes people feel sad, sometimes people feel mad. We can have many different feelings.

* **Facilitator's Note:** If appropriate, may use conversation to explore child's concern about how their siblings or parents might be feeling.



5. How do you think the children feel when their Mom or Dad is sad about kidney disease?

It's normal to feel sad sometimes.



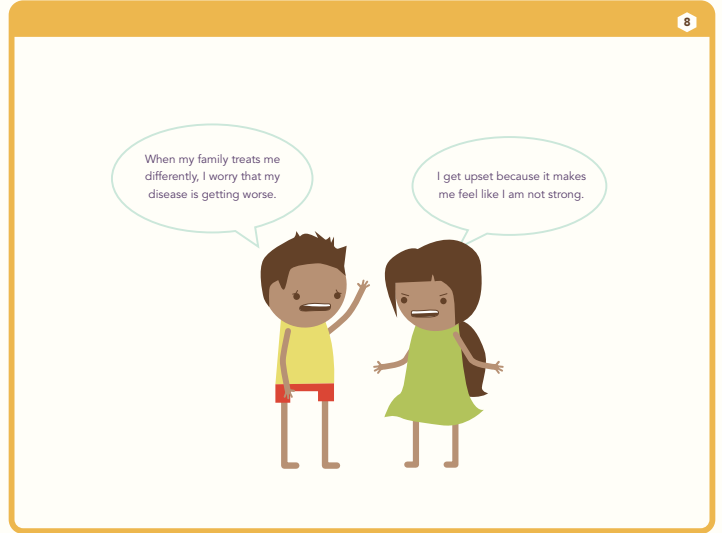
6. Everyone has many different feelings about kidney disease. Do you have different feelings about kidney disease? Your family has different feelings too. Sometimes they are sad too.

Do you ever think about that?



7. Does this ever happen to you?

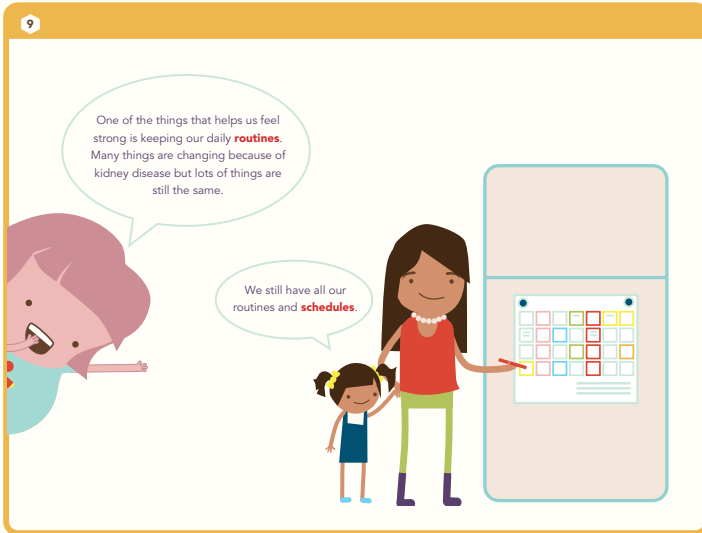
How does it make you feel when people feel sorry for you because you have kidney disease?



8. Sometimes people forget that your kidney disease is only part of life, not all of life. What would you like to tell people?

It takes time to make kidney disease part of your life but, step-by-step, the disease becomes just part of your life.

Does your family treat you the same as your brothers and sisters? Families help us.



9. Keeping many of your routines and building on them helps you with your kidney disease. Do you know what a routine is? A routine is something we do regularly.



10. For example, what are some routines you do every day?

- Have breakfast
- Brush teeth
- Get ready for bed

Now, every day, you add taking medicines before breakfast and at bedtime – it's building on your routine.



11. 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. It can also really help to talk to other people going through what you are going through.

There are also other ways to learn about your kidneys and health. What are some of those ways for you?

If you need some help, who would you ask?

See if child or parent comes up with ideas.


- * **Facilitator's Note:** For parents, sometimes the hardest part is asking for help.

UP NEXT: ADOLESCENT LEVEL

ADOLESCENT LEARNING

FAMILY COPING RESOURCES

ADOLESCENT LEVEL



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

ADOLESCENT LEARNING OBJECTIVES

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

The Adolescent 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

Possible activities include:

MY APPROACH

1. Review Motivational Interviewing.
2. Assess where family is at (Stages of Change).
3. 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. 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. 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 are turned down. Give opportunities to use strategic thinking, reasoning and problem solving. Let them do some evaluation and monitoring of their understanding.
7. While your time is limited, try to give children and family time to think about the material and messages.

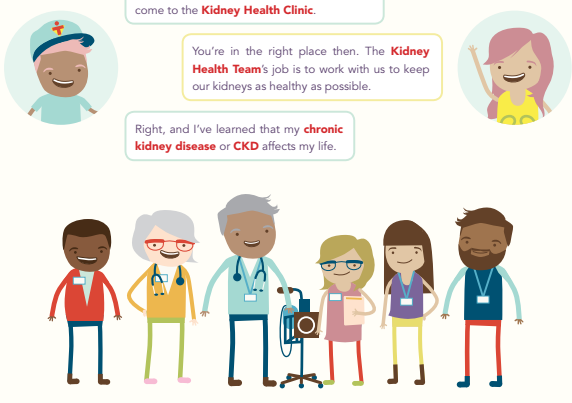
LEARNING SUPPORTS

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

SOCIAL WORK SUGGESTIONS

1. 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.
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



I have some trouble with my **kidneys** so I come to the **Kidney Health Clinic**.

You're in the right place then. The **Kidney Health Team's** job is to work with us to keep our kidneys as healthy as possible.

Right, and I've learned that my **chronic kidney disease** or **CKD** affects my 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.

2



It's scary sometimes. If I feel sick, I don't know if it's serious or what I should do.

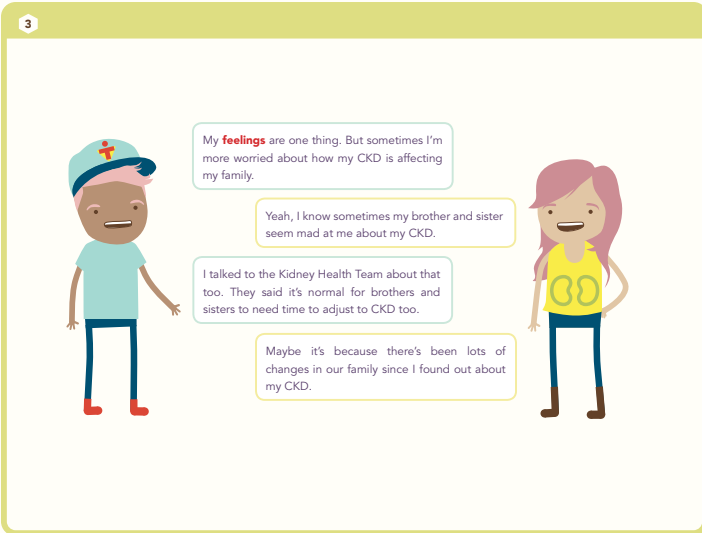
That's why it's a good idea to have a plan of who to talk to. My Kidney Health Team told me I should always tell an adult so they can help me make a good decision.

Who do you talk to?

2. A big part of coping with a chronic disease is planning and communicating. You and your family and us – your Kidney Health Team – can plan who to talk to when you need some support.

Who are some people in your life that you feel comfortable talking to?

These people need to know that you trust them and might need to tell them about how you're feeling. They might need to help you.



3. There are lots of feelings when people have a disease. The disease affects everyone in the family – everyone has to do things to live with kidney disease.

Sometimes people feel sad, sometimes people feel frustrated, sometimes people feel angry. There are many different feelings.

* **Facilitator's Note:** If appropriate, use to explore child's concern about their siblings or parents might be feeling.

4. How do you think the kids feel when their Mom or Dad is sad about kidney disease? Or when the parents are arguing a lot?

It's normal to feel sad sometimes.

It's no one's fault about kidney disease. It takes time for everyone to adjust and everyone will handle it differently.

We need to support each other in a family. It helps to be able to talk to each other about how we feel.



5. It's also normal to have many different feelings about kidney disease. Do you have different feelings about kidney disease?

Your family has different feelings too. Sometimes they are sad or upset too.

Dealing with the changes that come from a chronic disease can be hard on people and can affect relationships. You might be seeing some of that.

Do you ever think about that?



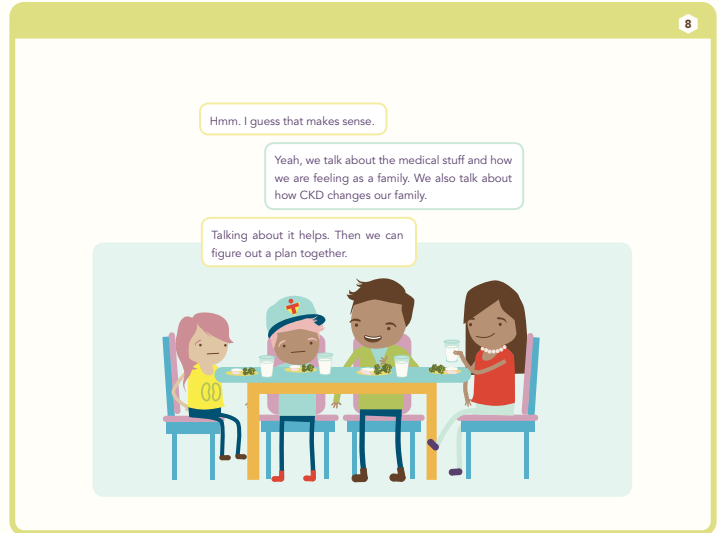
6. Does this ever happen to you?

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



7. Sometimes people forget that your family is still a regular family. Everyone and every family has different things they live with.

Your parents and your family might need to do things a little differently but you can still do all the things you used to do together. You might need to remind other people about that.



8. Your parents and your family might need to do things a little differently but you can still do all the things you used to do together. You might need to remind other people about that.

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.

Strong families help with living with all the changes that come from a chronic illness. Routines help give everyone some stability; having regular meals, for example, gives everyone a chance to talk and deal with kidney disease together.

Routines and building on them helps you and your family cope with the changes that come from your kidney disease. What are some routines you do every day?

- have breakfast
- brush teeth
- get ready for bed

Now, every day you add taking medicines before breakfast and at bedtime – it's building on your routine.

If you need some help, who would you ask?

See if child or parent comes up with ideas.

*** Facilitator's Note:** For parents, sometimes the hardest part is asking for help.



9. Part of living well with a chronic disease is finding ways to cope. There are stressful things about living with the disease – not just for you, but for everyone in your family too.

What do you think about that?

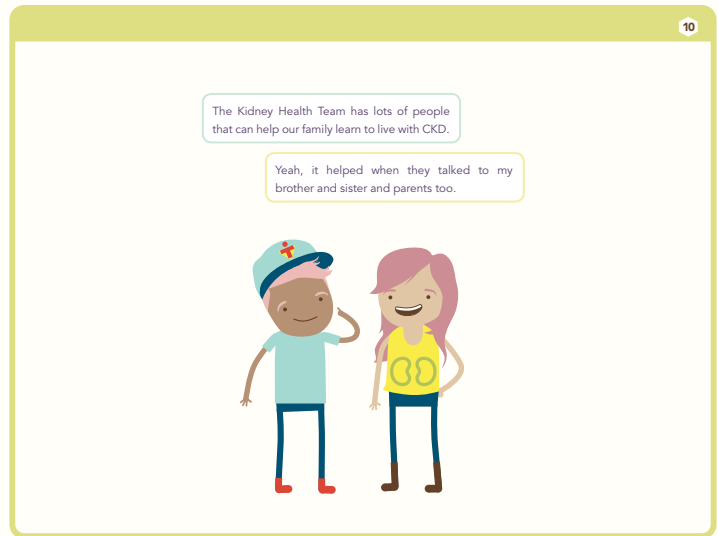
Everyone will find different ways of coping too. Some people write in a journal; some people talk; some people get very quiet. It's important to get some of your feelings out.

Do you do that?

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

Kidney disease is only part of life, not all of life. What do you think about that?

It takes time to make kidney disease part of your life but step-by-step, the disease becomes part of your life rather than all your life.



10. 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.

The whole Kidney Health Team can talk to you or your parents or your sisters and brothers about these things. There are social workers here and maybe in your community that you can talk to.

What resources could you use in your town or neighbourhood?

Sometimes it might not feel so private talking to someone in your community, so there are different people you can talk to by phone.

- * **Facilitator's Notes:** Acknowledge that privacy can be a challenge in small communities. What are options?

helplines • online resources • libraries • Children's Hospital Library • May want to suggest Kidney Connect <http://kidney.ning.com> (online) or by phone: 1-866-390-7337 (PEER) • May want to suggest KidsHelpPhone.ca 1-800-668-6868, Teens can also post questions: <http://www.kidshelpphone.ca/Teens/AskUsOnline.aspx>

Caution people to be careful not to share too much personal information on online forums

Let families know that the Kidney Health Team can help them figure out if the source they are using is trustworthy.

11

We aren't alone. There are lots of families living with CKD.

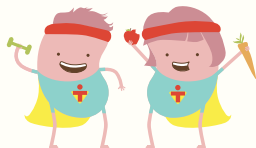
It's a family affair. The Kidney Health Team helps us figure it out.



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

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

We are here to help your whole family.



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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>