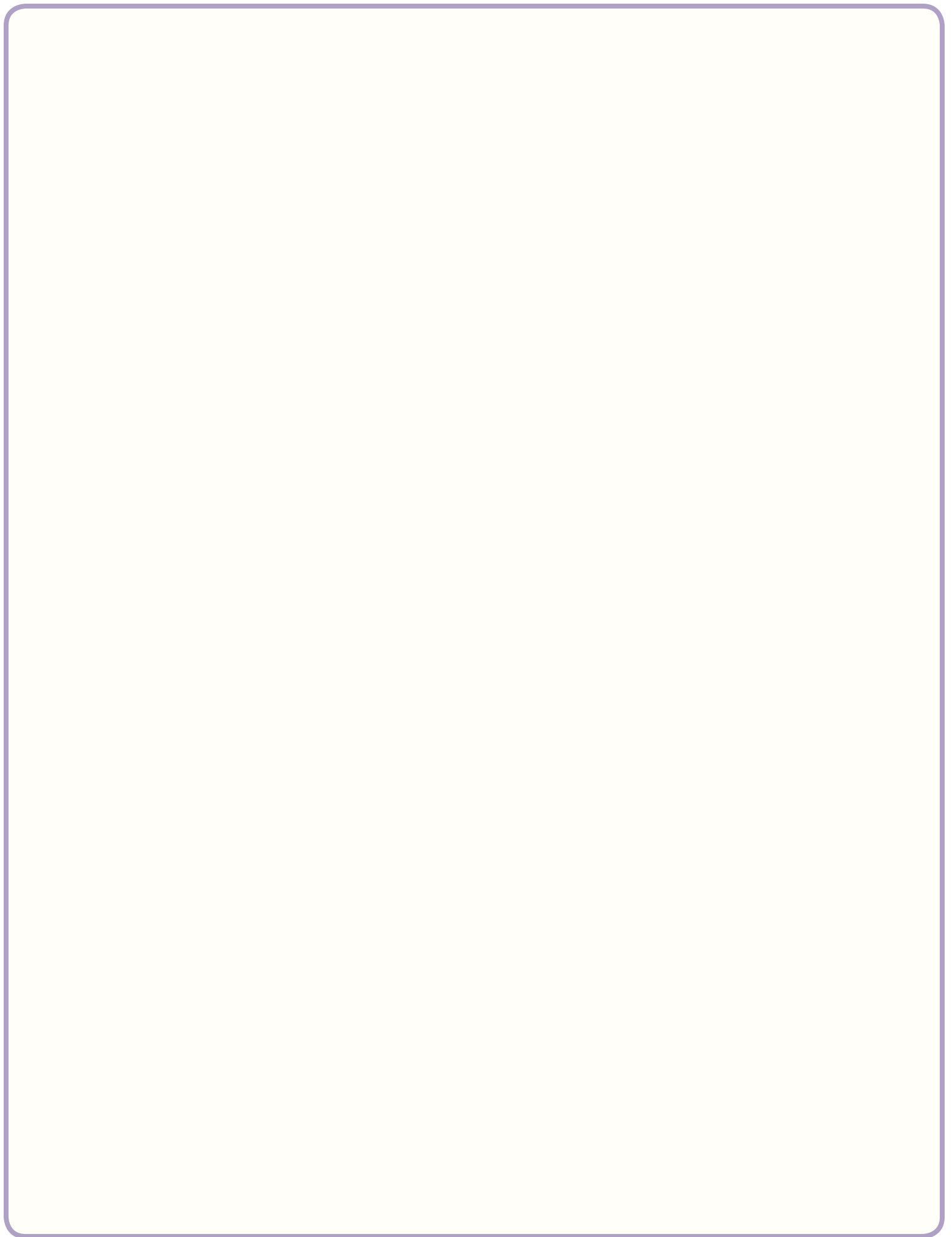




# TAKING MEDICINES

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



## 7. GLOBAL LEARNING OBJECTIVES

By the end of this session, the children and their family will be able to select options and strategies to improve their medication adherence.

Supports: Provide several options to choose from: alarms, 1 hour after medication is due; link medications w/ activities (brushing teeth, etc); pill boxes; consolidate medications and times; apps; emergency supplies; how to take medications in public (school / with friends);

## KIDNEY HEALTH MODULES DESIGN OVERVIEW

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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

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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

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### 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**

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By the end of this session:

**The Pre-School Age Child will be able to state:**

- a) medicines help your body when you need them
- b) medicines are not candy

**Possible activities include:****The School Age Child will attain Pre-School Age objectives and:**

- a) will cooperate with Mom or Dad or caregivers to take medicines
- b) point to their medicines when Health Care Professional names them
- c) know the times of the day they get their medicines

**Possible activities include:****The Adolescent will be able to attain School Age objectives and:**

- a) name their medications
- b) use strategies for medication adherence that work for them
- c) use strategies for problem - solving: taking medications at a friend's house; going on holiday; etc

**Possible activities include:** phone the pharmacy and ordering refills (with supervision); fill their pill box with supervision

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

- a) be responsible for supervising taking medications
- b) supporting children as they work towards independence with medications
- c) know medications and dosages to discuss with health care professionals

## KEY MESSAGES

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1. Kidney disease is chronic. Once you are on medicines to treat one of the co-morbidities, a child is likely to need the medicines long-term. Some of these medicines are prescribed with the intent to also delay the progression of kidney disease.
2. Adherence means sticking to the health care plan! People who are adherent are more likely to feel better and have better long-term health outcomes related to kidney disease.
3. Some kids are at higher risk of non-adherence and we need to be aware of those kids at risk in order to address their specific needs. The health care team is responsible for assessing the risk profile of each patient.
4. Assessment of non-adherence requires understanding the different types of non-adherence\* and the reasons that might be associated with these non-adherence patterns. These non-adherence patterns may be medication or treatment specific.
5. Parents or guardians are responsible for ensuring medication adherence. Parents should support teens in developing independence.
6. Adolescence and transition of care to adult medicine represents a high-risk time period for non-adherence, and requires careful additional attention. There is a stepwise approach to transitioning the independence from parent/guardian to the teen.
7. Health care team has a major role to identify non-adherence patterns amongst children/caregivers, and to provide strategies to improve adherence. This includes ongoing monitoring of the effectiveness of these strategies.
8. Open ended, non-judgmental and non-directive questioning will yield most accurate adherence information.
9. An important strategy to improve adherence is the development of structures and routines that help to incorporate medication patterns into daily living.
10. Motivational interviewing by the health care provider is the preferred approach to achieving long-term improvements in adherence. This includes assessing readiness for change.
11. We will utilize allied health team members such as child life therapist to assist with pill taking or fears and pharmacist for medication teaching and strategies for med adherence.
12. There are clinical tools available to assess adherence, for use in clinic.
13. Some reasons for non-adherence include:
  - o Medication side effects
  - o Lack of knowledge or understanding about the meds
  - o Financial
  - o Psychosocial
  - o Peer pressure – not wanting to be different
  - o Denial
  - o Medication regimen complexity (dosing frequency)
  - o Medication taste/swallowing difficulties.



### KEY MESSAGES CONTINUED ...

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14. Some strategies to aid in medication adherence include:
  - o Pill boxes
  - o Bubble packs
  - o Med Alarms
  - o Apps
  - o Med Buddies

### TARGETS FOR FACILITATORS TO BE AWARE OF

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1. The goal is to achieve 100% medication adherence.
2. Some blood tests measuring normal body functions will indicate levels of adherence to specific therapies (e.g. phosphate control).
3. We can utilize therapeutic drug monitoring to assess the level of intensity related to certain medications – high variability in these drug levels can be an indication of non-adherence.
4. There are physical signs that are related to adherence in some medications – their absence may signal non-adherence (e.g. steroids).
5. Physical signs may develop related to persistent non-adherence that are specific to the purpose of the medication (e.g. BP meds and headache/cardiac disease).
6. Stage of readiness for change as determined via motivational interviewing will determine what type of intervention is most appropriate at the moment.
7. Medication refill history can be used to track prescriptions (DPIN, eChart).
8. Clinic no-show rates may be an indicator of non-adherence.
9. Medication electronic monitoring (e.g. eCAP) can indicate the level of adherence.

## PRE-SCHOOL LEARNING

### 1. PRE-SCHOOL LEVEL

2. MEET YOUR KIDNEYS!



**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 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 state:**

- a) medicines help your body when you need them
- b) medicines are not candy

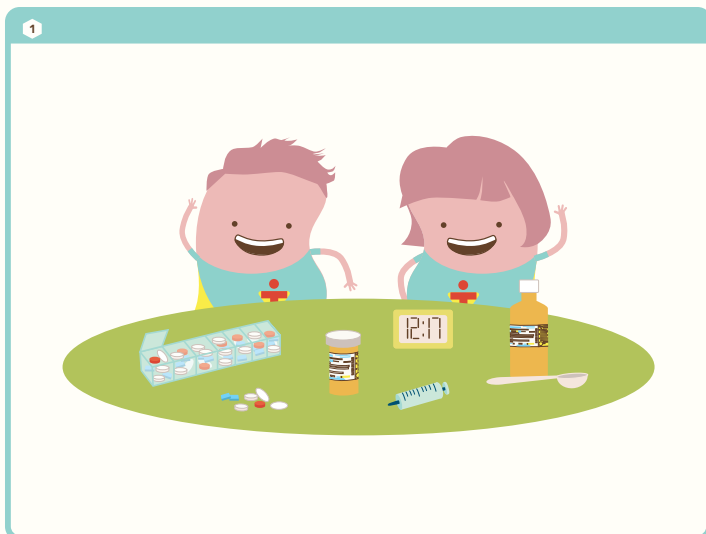
**Possible activities include:**

## 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.
4. Acknowledge what children do or say.
5. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
6. Ask questions to provoke thinking; 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?** Provide visual supports for strategies where possible: alarms; link medications w/ activities (brushing teeth, etc); pill boxes; consolidate medications and times; apps; emergency supplies; how to take medications in public (school / with friends);



1. Here are the Kidney Twins saying hello. What do you see on the table in front of them?

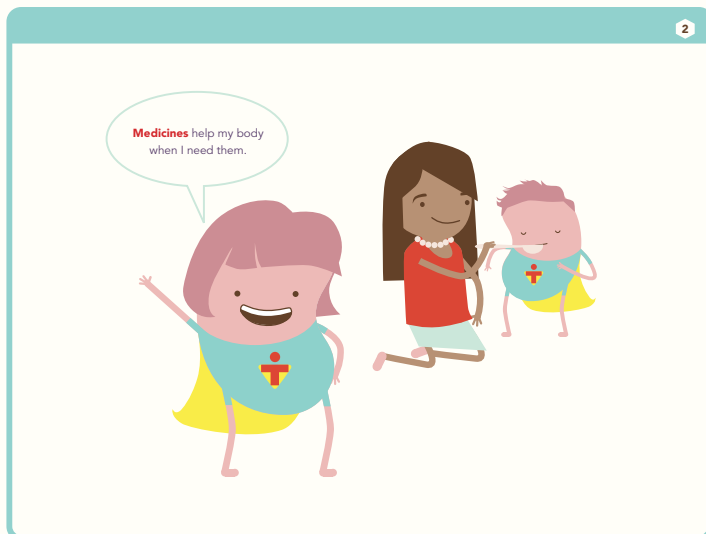
Possible responses:

- Medicines
- A needle / syringe
- I don't know
- Candy

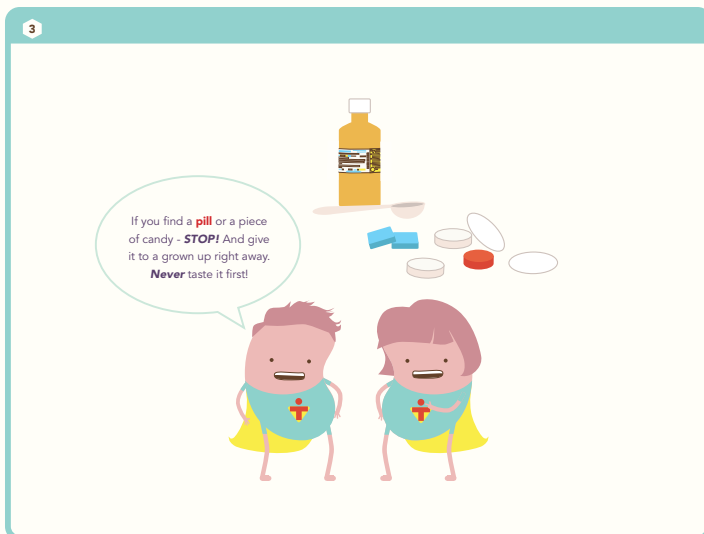
Good ideas. The Kidney Twins are looking at different medicines.

\* **Facilitator Note:** A study presented at the American Academy of Pediatrics Conference (Oct 2011) noted that students distinguished candy from medicines correctly 71% of the time, teachers at 78%.

<http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Teachers,-Children-Mistake-Candy-for-Medicine-in-Study.aspx>



2. Sometimes our bodies need help. We take medicines to help our bodies. We have to be careful to follow the instructions about taking the medicine.



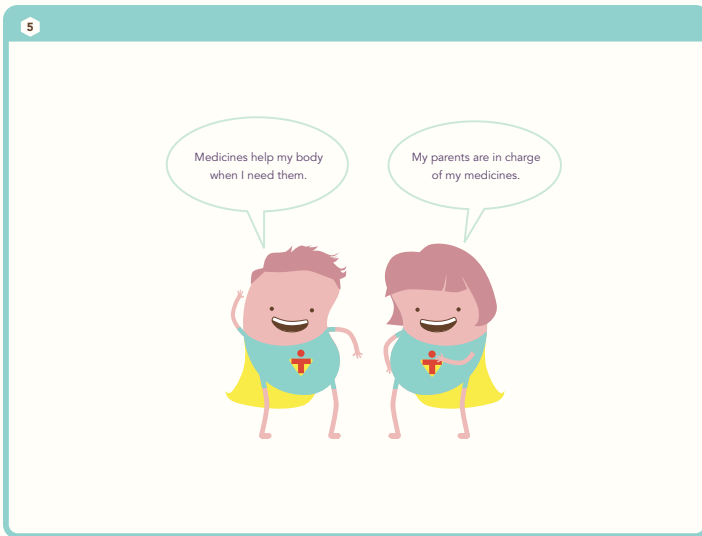
3. Medicines can look like candy – sometimes they are bright colours and interesting shapes. If you find a pill, give it to a grown up, don't try eating it.

Your medicines are only for you. You should take medicines only when your Mom or Dad brings the medicine to you.



4. Everyone in the house needs to know your medicine is only for you.

*To Parent:* Make sure and store medicine out of reach of young children.



5. Medicines help your body when you need them. Your Mom or Dad will give you the medicines when you need them. Remember, medicines are not candy.

*To Parent:* You need to bring all medicines to every clinic appointment.

## SCHOOL AGE LEARNING

### 2. SCHOOL AGE LEVEL

7. TAKING MEDICINES



**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

## 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 attain Pre-School Age objectives and:

- a) will cooperate with Mom or Dad or caregivers to take medicines
- b) point to their medicines when Health Care Professional names them
- c) know the times of the day they get their medicines

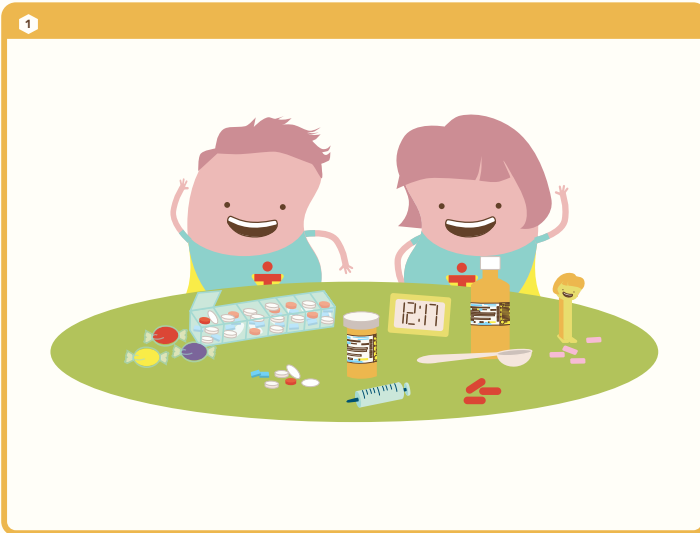
**Possible activities include:**

## 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. Provide information, directly giving children facts, labels and other information.
5. Ask questions to provoke thinking; ask children to 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?** Provide several options to choose from: alarms; link medications w/ activities (brushing teeth, etc); pill boxes; consolidate medications and times; apps; emergency supplies; how to take medications in public (school / with friends);



1. Here are the Kidney Twins saying hello. What do you see on the table in front of them?

Possible responses:

- Medicines
- A needle / syringe
- I don't know
- Candy

These could be medicines or they could be candies. Sometimes, it is hard to tell what is medicine and what is candy.

- \* **Facilitator Note:** A study presented at the American Academy of Pediatrics Conference (Oct 2011) noted that students distinguished candy from medicines correctly 71% of the time, teachers at 78%.

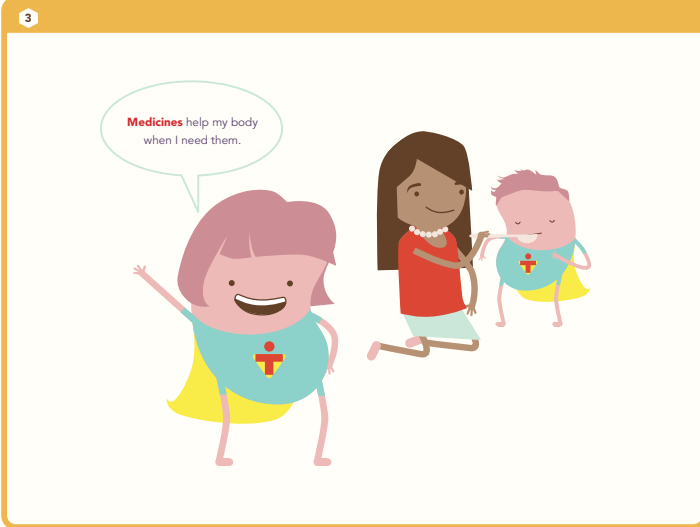
<http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Teachers,-Children-Mistake-Candy-for-Medicine-in-Study.aspx>



2. What should you do if you find something that looks like candy?

*Let child think for a moment.*

You should always give it to an adult and never taste it first.



3. Sometimes our bodies need help. We take medicines to help our bodies. We have to be careful to follow the instructions about taking the medicine.



4. What do you do when your Mom or Dad brings you medicine?

*Give child time to respond.*

- \* **Facilitator note:** If there are challenges with taking medicine, use opportunity to find out why before you can strategize how to improve adherence:

Some reasons for non-adherence include:

- Medication side effects
- Lack of knowledge or understanding about the meds
- Financial issues
- Psychosocial issues
- Peer pressure – not wanting to be different
- Denial
- Medication regimen complexity (dosing frequency)
- Medication taste/swallowing difficulties



5

Date: _____		Kidney Medicines Schedule													
Drug	Dose Times	Mon	Tues	Wed	Thu	Fri	Sat	Sun	Mon	Tues	Wed	Thu	Fri	Sat	Sun
		<b>Oxybutyryn 5 mg tablets</b> Give 1 tab THREE times a day (for urine flow)	breakfast	✓	✓	✓									
	supper	✓	✓	✓											
	bedtime	✓	✓	✓											
<b>Ferrous sulphate 300 mg tablet</b> Give 1 tablet TWO times a day (iron supplement)	breakfast	✓	✓	✓											
	bedtime	✓	✓	✓											
<b>Sodium citrate 1 mmol/mL oral solution</b> Give 25 mL TWO times a day (for acid/base balance)	breakfast	✓	✓	✓											
	bedtime	✓	✓	✓											
<b>Replivite tablets</b> Give 1 tablet ONCE daily (vitamin supplement)	breakfast	✓	✓	✓											
<b>Calcitriol 0.25 mcg capsules</b> Give 1 capsule ONCE daily (for bone health)	breakfast	✓	✓	✓											
<b>Amlodipine 5 mg tablets</b> Give 2 tablets (10 mg) ONCE daily (for high blood pressure)	bedtime	✓	✓												
<b>Vitamin D 1,000 unit tablets</b> Give 1 tablet ONCE daily (for bone health)	breakfast	✓	✓	✓											

Do you know the names of the medicines you take?

My parents and I made a **chart** for medicines I need every day so I can start learning the names.

6

My parents will have to figure out what will work best for us so I always get my medicines on time.

I swallow **pills** so my parents use a **pill box**. They say that's the easiest way to keep track of my medicines.

5. As you get a little older, you can start to learn the names of the medicines.

**Activity:** Using medicines that parent brought to appointment, say the names out loud and ask child (and parent) to point to the medicine.

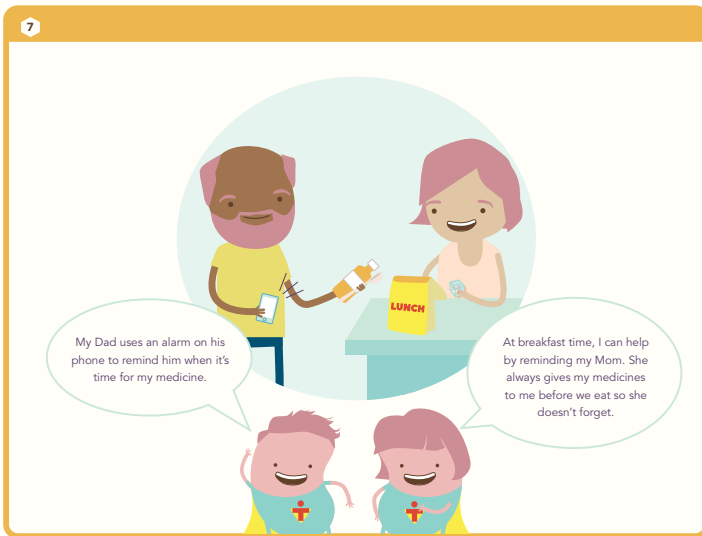
\* **Facilitator Note:** Have sample medicines for that child in case parent did not bring medicines to appointment.

Ask if the family uses a chart like the one in the module. The Kidney Health Team can help prepare one if the family is interested.

6. Over time, your family will learn what strategies will help you make sure you get the medicines you need when you need it.

*Families can consider:*

- pill boxes or organizer
- alarms
- medicine schedule on paper
- apps
- blister or bubble packs



**7. How do you think it will be easiest for you to stick to your medicine schedule?**

Other families have told us that tying medicines to another routine is very helpful.

- before mealtimes
- before brushing teeth
- before leaving for school
- before going to bed

Remember the Kidney Health Team is here to help. We have worked with lots and lots of families who learn to manage taking medicines.

Do you have questions?


*Review Parent and Caregiver Resource.*

**UP NEXT: ADOLESCENT LEVEL**

## ADOLESCENT LEARNING

### 3. ADOLESCENT LEVEL

7. TAKING MEDICINES



RESOURCES MENU

1. Your Kidney Health Team
2. Meet Your Kidney!
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## ADOLESCENT LEARNING OBJECTIVES

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

The Adolescent will be able to attain School Age objectives and:

- a) name their medications
- b) use strategies for medication adherence that work for them
- c) use strategies for problem - solving: taking medications at a friend's house; going on holiday; etc

**Possible activities include:** phone the pharmacy and ordering refills (with supervision); fill their pill box with supervision

## 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. Acknowledge what the adolescents say and do. Model attitudes, ways of approaching problems and behaviours 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. 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?** Provide several options to choose from: alarms; link medications w/ activities (brushing teeth, etc); pill boxes; consolidate medications and times; apps; emergency supplies; how to take medications in public (school / with friends);

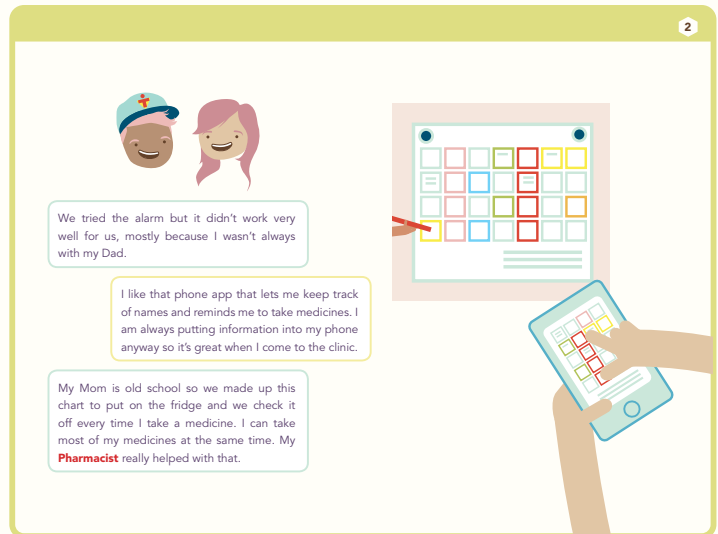


1. Today we are going to talk about taking medicines and strategies – or plans – to help you take your medicines on time and as the Doctor has prescribed.

First of all, why is it important you take your medicines?

Medicines help your body get something it needs. Sometimes your body cannot make what it needs or cannot use it so medicines help, even if we do not feel the difference.

- \* **Facilitator Note:** Give adolescent time to air concerns, frustrations, ideas.



2. Taking medicines is an important part of keeping healthy. We have to find ways to make sure you take the medicines you need when you need them. It is important to take medicines the same way every time.

There are many different ways to make sure you take the medicines you need to.

We will work with you to figure out what will work best for you.

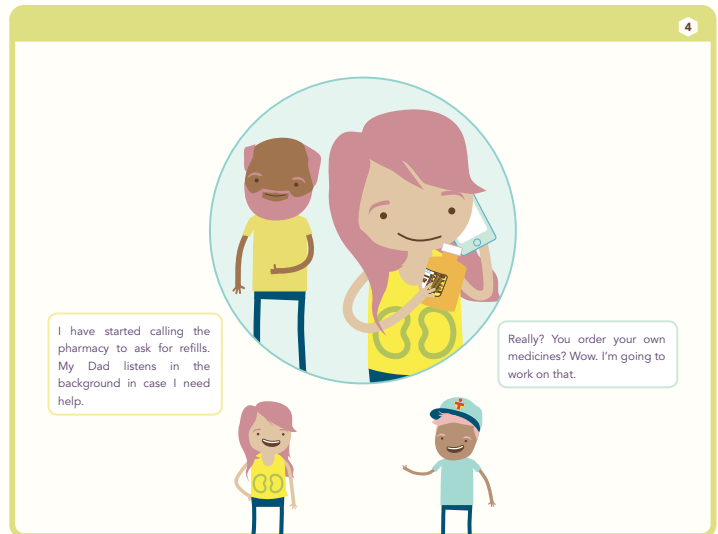
What do you think?

- \* **Facilitator's Note:** The most important message is to take the medicines the same way every time: 1) so patient develops a pattern for schedule 2) so the medicine works the same each time the patient takes it.



3. There are many things to do that make it easier to keep your medicines organized and make sure you take them when you need to.

- **Facilitator's Note:** Some families will prefer to use blister packs made by the pharmacy to organize their medicines. Possible downsides to blister packs include:
  - people do not know their medications as well;
  - packages are bulky to carry
  - medicine changes are harder to make



4. Sometimes it takes the pharmacy a few days or weeks to get the medicines.

When you fill up pill boxes for the week, it helps you know how much medicine you have left. If you are getting low, you can phone the pharmacy in time.


5

When I am going to be away from home, it can get kind of hard to stay organized. I need to take my pill bottles.

Yes, my Pharmacist says to always take a few extra days of medicine with you. If you plan to be gone for 4 days, take the full 7-day pill box anyway.

The best thing is to plan: check that I have enough pills and pill boxes. My parents talk to my Auntie to make sure she knows who to call if there are any questions.

I need to get some extra pill boxes!



The illustration shows a pharmacist in a blue cap and a customer with pink hair. Between them are three medicine bottles (green, orange, and blue) and a blue pill box with several compartments containing white and red pills.

5. How do you think you can prepare going to stay with your Grandma or a friend?

*Problem-solve together.*

6

I've been trying to learn the names of my medicines but it's hard! I keep trying because I know how important it is to know them.

It's a lot easier to take my medicines now that I know what I take them for and how they help me.



The illustration shows a pharmacist in a blue cap and a customer with pink hair standing behind a counter. On the counter are several medicine bottles and a pill box. A question mark is above the pharmacist's head.

6. Let's look at your bag of medicines. We can go through them together, work on learning the names and talk about how they help you.

7

Keeping my **kidneys** healthy means I have to get my medicines at the right times. We can do it! Here are some tips:

#### Tips for Taking Medicines

- Make a **schedule** of all your medicines and the times you need to take them
- Take medicine with something else you do regularly, such as eating or brushing your teeth
- Keep all medicines together
- Prepare your medicines for each week with a pill box (or **bubble pack**)
- Use **reminders** to check that you took your medicines on time
- Ask your **Kidney Health Team** for more tips!



7. Together, we can help you figure out the best ways of managing your medicines.

What do you think?

8

It got easier to get my medicines right, especially with help from my Kidney Health Team. There are lots of "strategies" for me and my parents to use.

The **most important** things for taking medicines:

- plan your schedule and reminders
- use pill boxes to organize your medicines
- know what you take your medicines for

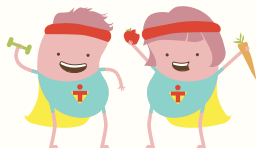


8. We know that having a routine makes it easier to take your medicines regularly. We also know that there are other strategies or plans for helping you take your medicines as your Doctor prescribes.

We can work together to figure out what will work best for you and your family.

*Families can consider:*

- pill boxes or organizer
- alarms
- medicine schedule on paper
- apps
- blister or bubble packs



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](mailto:jstrong@exchange.hsc.mb.ca) or the Children's Hospital Foundation of Manitoba <http://goodbear.mb.ca>