

PARENT AND CAREGIVER RESOURCE

# **PARENT AND CAREGIVER 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

Taking **medicines** is something that will be part of your life when your child has kidney disease. Medicines are prescribed to provide something the body needs. Once medicines are prescribed, your child will likely need the medicines long-term. Some of the medicines are prescribed to try to slow down the **progression** of kidney disease in your child.

It is important that medicines are used properly. For younger children, make sure they understand that medicine is not candy. Store medicines in the same place and out of reach of small children.

Every family will find strategies that work best for them. For some families, **bubble packs** (**blister packs**) work well. Other people prefer **pill boxes**. Some families like keeping track of medicine **schedules** using apps or technology, while others like to make a **chart** that can be posted somewhere everyone can see it.

Using reminders like an alarm to check that you took

your medicine is really helpful. The alarm goes off a little after the medicine was due and it reminds you to check if the medicines was taken.

When schedules change – for travelling or a special event – the family routine changes and this usually affects taking medicines. The best option is to plan in advance. Planning in advance also helps make sure your child always has the medicines he or she needs. If you run into problems with your pharmacy not being able to get medicines, contact the **Kidney Health Team** to help with a solution.

When you are travelling – like coming to appointments in the city - always have at least an extra week of medicines with you. Carry your child's medicines in your carry-on or hand luggage, not in your suitcase. Even if you have put your child's medicines in a pill box for the week, you should also bring the original medicine bottles with your child's name and information on them.

The Kidney Health Team will continue to work with you to help you understand your child's medicines. It is important to know:

- the names of the medicines
- what the medicines are for
- the **dosage** your child needs
- when the medicines should be taken

You will learn about your child's medicines over time.

You will need to support your child as they work towards independence with taking and organizing medicines. For example, you can involve your child in filling pill boxes for the next week and saying the names of the medicines and what they are for together. You could also practice calling the pharmacy together for a **prescription** refill.

When working with your teen, you can check the blister pack or the pill box to see if your teen has taken their medicines. You can give them the medicine if they have forgotten and reward them when they are doing well to remember themselves.

Remember, with teenagers, parents are still responsible for making sure medicines have been taken. You will be helping your teen develop the skills to manage their medicines themselves eventually. They still need your guidance and support.

You are responsible for supervising your child at any age taking medicines.

It is your responsibility to bring all your child's medicines to each clinic appointment.

WEB BASED RESOURCES

http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingOver-the-CounterMedicines/ucm094876.htm#11

As They Grow: Teaching Your Children How to Use Medicines Safely (adapted from the United States Pharmacopeia)

http://www.kidney.ca/document.doc?id=332, page 13
Your Child and Chronic Kidney Disease (Search for apps using "medication tracker" or "med organizer")

http://www.aboutkidshealth.ca/En/HealthAZ/Pages/default.aspx Click on the Letters A-Z to find information on health related topics

http://www.caringforkids.cps.ca/ Click on a variety of topics at the top of the website for general information to parents about child health. From the Canadian Pediatric Society

http://www.cheo.on.ca/en/activitysheets Helping Medication Taste Better

As They Grow: Teaching Your Children How to
Use Medicines Safely http://www.fda.gov/Drugs/
ResourcesForYou/Consumers/BuyingUsing Medicine
Safely/UnderstandingOver-the-CounterMedicines/
ucm094876.htm#11

https://www.medactionplan.com/ped/

https://secure.medactionplan.com/mymedschedule/

https://medicalert.ca/

www.identifyyourself.com

http://www.cw.bc.ca/library/pdf/pamphlets/BCCH196Medicine.pdf

http://www.freeprintablebehaviorcharts.com/

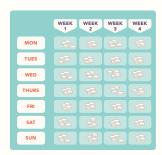
http://kidney.niddk.nih.gov/kudiseases/a-z.aspx

http://www.youtube.com/watch?v=MXFMZuNs-Fk

# PARENT AND CAREGIVER RESOURCE

http://kidneyweb.net/handouts.htm
HANDOUTS
Kidney Foundation Booklet: "Your Child & Chronic
Kidney Disease" <a href="http://www.kidney.ca/document.doc?id=332">http://www.kidney.ca/document.doc?id=332</a>
APPS
My Med Rec (Apple or Android)
iPharmacy
CONSULTS TO OTHER HEALTH CARE PROFESSIONALS
Pharmacy consult re med teaching
Child Life consult re pill swallowing

# TAKING MEDICINES GLOSSARY



#### **BLISTER PACKS**

Blister packs are packages put together by the Pharmacist with all of our medicines sorted out. Each blister pack will contain a one-week supply of medicine. The blister pack will usually have 4 slots for medicines for each day. If medicine needs to be protected from air or light they will sometimes come in their own blister packs right from the company that makes them.



#### **BUBBLE PACK**

Bubble pack is another way of saying blister packs. (See blister packs).



#### **DOSAGE**

The dosage is the amount of medicine you need to take and how often you need to take that amount of medicine.



#### **KIDNEY HEALTH TEAM**

Kidney Health Team is all the different people who work with you to help keep your kidneys as healthy as possible. Members of the Kidney Health Team include nurses, doctors (nephrologists), dietitians, social workers, clerks, you and your family. Together, everyone will work with you to make your Kidney Health Care Plan.



#### **KIDNEYS**

Kidneys are bean-shaped organs about the size of our fist. Most people have 2 kidneys. Kidneys are found under the rib cage near the middle of the back. The kidneys have many functions or jobs (see Kidney Function).

## PARENT AND CAREGIVER RESOURCE





#### MEDICINE(S)

Medicines can have many forms like pills, liquids, creams, injections or puffers. Medicines are prescribed by a doctor to treat different problems. Some medicines are only taken for a short time, like when you have an infection. Other medicines become a regular part of life, like treating asthma or taking vitamins. We should always take medicines the way the doctor prescribes them.



#### **PHARMACIST**

Pharmacists are members of your Kidney Health Team. Pharmacists read the prescription from the Doctor and give you your medicines and instructions.





Pills are medicines that we swallow. They are also known as tablets, capsules, or gel caps. Pills might be different shapes (round, long and skinny, football-shaped, etc.) and different colours. Pills should be stored safely. Pills should only be taken as directed by your health care team or the Pharmacist.



## PILL BOX OR PILL ORGANIZER

A pill box or pill organizer is a container used to plan daily pills to help stay organized so we know if we have taken our pills or not.



# **PRESCRIPTION**

Prescriptions are a set of instructions for a pharmacist to prepare medicines properly. A prescription is usually written or typed on paper by the doctor.



#### **PROGRESSION**

Progression means to move or develop to a more advanced level. Progression is usually gradual or happens in stages. When we talk about CKD progression it means that the kidney function is getting worse, like going from mild kidney failure to moderate, or more severe kidney failure. In some cases, progression of CKD continues until you need dialysis or a kidney transplant to replace the kidney function.



#### **REMINDERS**

Reminders can help us check if we have taken medicine when you are supposed to. We can set an alarm for 15 minutes after we are supposed to take medicine. When the alarm goes off, it reminds us to check we have taken the medicine. If we have forgotten, we can take it then.

Nidney Medicines Schedule															
Drug	Dose Times	Mon	Tues	Wed	Thu	Fri	Sat	Sun	Mon	Tues	Wed	Thu	Fri	Sat	5
Oxybutynin 5 mg tablets Give 1 tab THREE times a day (for urine flow)	breakfast	$\vee$	$\checkmark$	$\checkmark$											
	supper	$\checkmark$	$\checkmark$												
	bedtime	$\checkmark$	$\checkmark$												
Ferrous sulphate 300 mg tablet Give 1 tablet TWO times a day (non supplement)	breakfast	/	/	1											
	bedtime	/	<b>/</b>												
Sodium citrate 1 mmol/ml, oral salution Give 25 ml. TWO times a day (for acid/base balance)	breakfast	<b>✓</b>	1	1					Г						Γ
	bedtime	<b>✓</b>	<b>✓</b>												
Replayte tablets Give 1 tablet ONCE daily (vitamin supplement)	breakfast	1	1	1											
Caldtriol 0.25 mag capsules Give 1 capsule ONCE daily (for bone health)	breakfast	/	/	1											
Amledgine 5 mg tablets Give 2 tablets (10 mg) ONCE daily (for high blood pressure)	bedtime	/	1												
Vitamin D 1,000 unit tablets Give 1 tablet ONCE daily (for bone health)	breakfast	/	1	1											

#### **SCHEDULE**

Schedules and routines are things we do regularly at the same time or date. Having regular schedules for eating together, going to bed and doing our homework helps us to stay organized. Having schedules and routines can make it easier to take medicines as they are prescribed.



#### **STRATEGIES**

Strategies help us deal with a challenge. It means to think about something that might happen and to make a plan for what you will do about it. It can be difficult to take our medicines on time, so trying different strategies until we find some that work for us and our families is helpful.









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