



# MY COPING RESOURCES

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
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Learning to live well with a **chronic disease** takes time, patience and flexibility. Your child will go through different phases of accepting the **chronic kidney disease (CKD)** that is part of their life. Your child's reaction to CKD will be affected by **developmental stage** and changes in their disease or health. Your response to the disease can affect how your child responds and how they see themselves. Your child will be responding to CKD in more than physical ways.

It is important for parents to understand that part of how your child feels emotionally is related to how they are feeling physically. Your child may be affected by feeling "different" from other children. The **Kidney Health Team** will likely be able to help your child deal with some of these feelings as we work with many children who have similar challenges.

We encourage your child to ask for help and to express emotions in a safe environment. It is important to identify supports outside the family too,

including friends and other important adults. There are many different members of the Kidney Health Team, each with different help to provide. The Team can also help identify and put you in touch with supports in your community.

Structure and **routine** help children feel secure. Providing structure in your home will help your child adjust to living with CKD. Talk with your children about how everyone does different things to stay healthy. For example, noticing that everyone does things to stay healthy - whether it is using an asthma puffer or not eating certain foods - will help.

Structure and routine help children feel secure. Providing structure in your home will help your child adjust to living with CKD. Talking with your child about how everyone does different things to stay healthy will also help your child experience living with a chronic disease as normal. Noticing that everyone does things to stay healthy - whether it is using an asthma puffer or not eating certain foods -

## MY COPING RESOURCES

will help.

As you know, living with your child's chronic kidney disease affects the whole family. While we provide "medical" care for your child, we are here to help the whole family learn to live well with your child's kidney disease.

### SUPPORT GROUPS

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**Kidney Connect** <http://kidney.ning.com> (online) or by phone: 1-866-390-7337 (PEER).

*A Peer Support Network supported by the Kidney Foundation of Canada.*

**KidsHelpPhone** 1-800-668-6868 <http://www.kidshelpphone.ca/Teens/AskUsOnline.aspx> (24/7, free, anonymous, for ages 20 & under)

### WEB BASED RESOURCES

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<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.aboutkidshealth.ca/En/JustForKids/Life/Pages/Puberty.aspx>

<http://www.aboutkidshealth.ca/En/HealthAZ/TestsAndTreatments/Procedures/Pages/Blood-Work-Helping-Your-Child-Get-Ready.aspx>

<http://www.aboutkidshealth.ca/En/HealthAZ/TestsAndTreatments/HealthCareProfessionals/Pages/Social-Workers-Can-Help-You-Cope-With-Illness.aspx>

<http://www.aboutkidshealth.ca/En/HealthAZ/DevelopmentalStages/SchoolAgeChildren/Pages/Social-and-Emotional-Development.aspx>

[http://www.cw.bc.ca/library/pdf/pamphlets/VCH\\_GK.300.G761.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/VCH_GK.300.G761.pdf)

*(Growing and learning Toddler)*

<http://www.aboutkidshealth.ca/En/HealthAZ/FamilyandPeerRelations/Pages/default.aspx>  
*From here you can click on topics related to topic*

<http://www.aboutkidshealth.ca/En/HealthAZ/FamilyandPeerRelations/BehaviourManagement/Pages/resilience.aspx>

<http://www.aboutkidshealth.ca/En/HealthAZ/FamilyandPeerRelations/AttachmentandEmotions/Pages/help-child-cope-with-emotions.aspx>

[http://www.caringforkids.cps.ca/handouts/talk\\_with\\_your\\_teen](http://www.caringforkids.cps.ca/handouts/talk_with_your_teen)

[http://www.caringforkids.cps.ca/handouts/mental\\_health](http://www.caringforkids.cps.ca/handouts/mental_health)

<http://www.aboutkidshealth.ca/En/HealthAZ/ConditionsandDiseases/BehaviouralandEmotionalProblems/Pages/Anxiety.aspx>

<http://kidneyschool.org/>

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

<http://kidshealth.org/>

### WEB BASED RESOURCES FOR KIDS

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<http://kidshealth.org/>

<http://www.aboutkidshealth.ca/En/JustForKids/Life/Pages/Puberty.aspx>

### HANDOUTS

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**Kidney Foundation Booklet: "Your Child & Chronic Kidney Disease"** <http://www.kidney.ca/document.doc?id=332>

## PARENT AND CAREGIVER RESOURCE

The following books are all available at the Children's Hospital Family Information Library. The library is in CK 204. The phone number is 204-787-1012.

**Easy for you to say: Q & As for teens living with chronic illness or disability** / by Kaufman, Miriam--Toronto,ON: Key Porter, 1995.

*Answers to many questions teens may have about their chronic illness or disability. Appropriate for Ages: 12-17 years.*

**Growing up strong** / by Burkett, Mary --Columbia,SC:R.L. Bryan, 1999.

*What every parent should know about self-concept in children with long-term illnesses.*

**Hi, my name is Jack: a book for the healthy siblings of chronically ill children** / by Beall-Sullivan, Christina --Park City,UT: Bopar Books, 2005.

*Eight-year-old Jack tells what it is like to have a sister who is chronically ill. Appropriate for Ages: 4-8 years*

**Teens face to face with chronic illness** / by Le Vert, Suzanne – New York: Julian Messner Press, 1993.

*Stories from teenagers about their chronic illness and a guide on how to cope.*

**Parenting children with health issues: essential tools, tips, and tactics for raising kids with chronic illness, medical conditions and special healthcare needs** / by Cline, Foster -- Golden, CO: Love & Logic Press, 2007.

*Offers parents of children with chronic health issues practical strategies and suggestions to help them cope with their child's condition and the constant physical and emotional challenges they face.*

**Sick all the time: kids with chronic illness** / by Chastain, Zachary -- Broomall, PA: Mason Crest Publishers, 2011.  
*Kids just want to be kids. They want to spend time with their friends and enjoy life. When a kid has a chronic illness, though, it can be a lot more difficult to do those things.*

**Young people and chronic illness: true stories, help, and hope** / by Huegel, Kelly -- Minneapolis, MN: Free Spirit Pub., 1998.

*Stories from adolescents about their chronic illness and a guide on how to cope. Appropriate for Ages 10-17 years.*

**Little Heroes: How We live With Kidney Disease** / available through the Section of Pediatric Nephrology – may require updating.

### APPS

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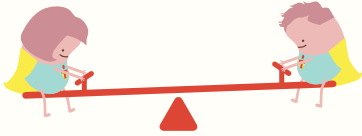
- Virtual Hope Box

### CONSULTS TO OTHER HEALTH CARE PROFESSIONALS

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- Child Life
- Psychiatry
- Social Work
- Kidney Foundation peer support

### MY COPING RESOURCES GLOSSARY



#### BALANCE

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Balance is when you have just the right amount of something - not too much, not too little. Our kidneys balance many things in our body.



#### BLOOD TEST

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Blood tests can check how well our body is working, whether we have enough or too much of certain vitamins and minerals and whether we might have an infection. A blood test is done by taking a small sample of our blood and testing it in a lab.

## CHRONIC DISEASE

#### CHRONIC DISEASE

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Chronic disease means that there is a part of the disease that will always be there. It can affect how the body works, sometimes just a little but sometimes a lot. If it is getting gradually worse, it is called progressive.



#### CHRONIC KIDNEY DISEASE

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Chronic Kidney Disease means that there is some damage to the kidneys that will always be there. It affects how well the kidneys can clean the blood to get rid of body waste and keep other body systems in balance. When the kidney function is lower, it is sometimes also called chronic kidney failure.

## CKD

#### CKD

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An abbreviation for Chronic Kidney Disease.

## CREATININE

#### CREATININE

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Creatinine is a body waste substance made by our muscles and is carried away from muscle in the blood. The kidneys normally clean creatinine out of the blood. If the kidney function is less, then creatinine builds up in the blood. We can measure the blood level of creatinine to tell us about the level of kidney function.



### FEELINGS

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Feelings are the thoughts and emotions we have inside ourselves. For example, sometimes we feel sad, sometimes we feel scared, sometimes we feel happy, sometimes we feel angry. Our feelings are our own and it's ok to feel how we feel. It can help to talk about our feelings.



### KIDNEY HEALTH CLINIC

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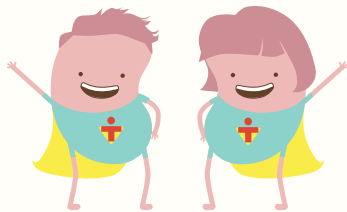
Kidney Health Clinic is a place where doctors, nurses and other members of the Kidney Health Team can see you to check on your kidney health and how you are doing.



### KIDNEY HEALTH TEAM

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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

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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).



### MEDICINE(S)

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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.



### MONITOR / MONITORING

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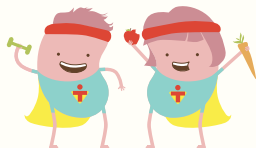
Monitoring means to watch and check regularly. When you have Chronic Kidney Disease, your Kidney Health Team monitors many things in your body.



### URINE TEST(S)

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Urine test is when you collect urine (also called pee) in a container and send it to the laboratory to check. Urine tests can check for many things such as protein, infection or the amount of urine you are making.



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>