



FAMILY COPING RESOURCES

PARENT AND CAREGIVER RESOURCE

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NOTES

RESOURCES MENU

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The diagnosis of **chronic kidney disease** or **CKD** impacts the whole family – it's often sudden and shocking. It's very stressful for everyone in your family. It is normal to grieve and feel tremendous loss: this is not what you hoped for for your child. It is normal for everyone to feel stress as you learn about CKD, go through treatments and make changes in your lives to live with kidney disease. There are many challenges for everyone in the family to cope with demands related to CKD.

As parents, 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 as well. 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.

Your family will likely feel grief and loss as you understand your child's diagnosis. It takes time to process how your life and your child's life might be

different than what you imaged. The Kidney Health Team, especially Social Workers, can help you as you go through different phases of adjustment.

Everyone in your family will likely experience many feelings at different times. People in your family might feel sadness, anger, confusion and fear at different times. For instance, one parent may not accept kidney disease, the other parent may be feeling very sad and a brother or sister might be feeling angry about all the special attention given to the child with CKD. The Kidney Health Team can help the whole family learn about living with CKD.

At the beginning, as your family learns to live with CKD, there will be many changes to your family **routines**. There are **medicines** to take regularly and probably changes to how your family eats. Everyone will be going through different emotional reactions too. You will likely be treating your child with kidney disease differently because you are worried about their health.

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Over time though, living with kidney disease in your family becomes normal. There will be adjustments to medicines and your child's kidney care plan. Having routines will help with these changes. If you want some help with structure in your family life, talk to us. We can help with strategies or accessing resources to help develop routines and structures in your home that will work for all of you.

How parents and extended family cope with the changes that come from living with CKD affects how your child will respond and cope with their disease. When the important people in your child's life are coping well with CKD, they are best able to help your child. The Kidney Health Team encourages your child to ask for help and to express emotions in a safe environment. Your child will need to come to you when they are scared or confused about their disease and how to cope with different things.

It is important to identify supports outside the family too, including friends and other important adults. Who are the adults your child can tell if they feel sick? These people need to know what to do if your child tells them they don't feel well. Make sure your child knows who to tell if they feel sick. Who are the people you can talk to? Where can you get good information?

There are many different members of the Kidney Health Team, each with different help to provide. 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 also here to help the whole family learn to live well with CKD. It's ok to ask questions and it's ok to express emotions. It can be difficult for siblings and we want to make sure they are included in discussions and have resources that help them too.

The Kidney Health Team can also help identify and put you in touch with supports in your community. You need to be able to get support as well. Talking with other families who have a similar experience might be helpful too.

Learning to live well with a chronic disease is all about dealing with change.

SUPPORT GROUPS

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

<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/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 (Growing and learning Toddler)

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

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<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/mental_health

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

<http://kidneyschool.org/>

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

<http://kidshealth.org/>

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

WEB BASED RESOURCES FOR KIDS

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

<http://kidshealth.org/>

HANDOUTS

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

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.

FAMILY COPING RESOURCES

APPS

- Virtual Hope Box

CONSULTS TO OTHER HEALTH CARE PROFESSIONALS

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

FAMILY COPING RESOURCES GLOSSARY



CHRONIC KIDNEY DISEASE

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

An abbreviation for Chronic Kidney Disease.



FEELINGS

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.



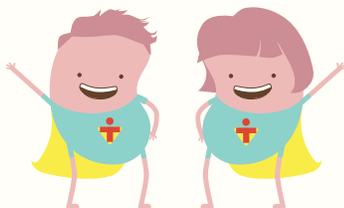
KIDNEY HEALTH CLINIC

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

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).



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.



ROUTINE

A routine is something that is done regularly at the same time or date. For example, brushing your teeth each morning at 8 am or eating dinner together or doing your homework from 4:30pm – 5:00pm each day are routines. Routines help us adjust to changes and to look after our health better.

Date: _____		Kidney Medicines Schedule						
Drug	How Often	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Oxycodone 5 mg tablets Give 1 tab. THREE times a day for pain relief	Breakfast	✓	✓	✓				
	Lunch	✓	✓	✓				
Fentanyl patches 50 µg patch Give 1 patch TWO times a day for pain relief	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				
Sulfamethoxazole 1000 mg and Trimethoprim 200 mg Give 25 mL TWO times a day for infection relief	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				
Naproxen tablets Give 1 tablet ONCE daily for pain relief	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				
Calcitriol 0.25 mcg capsules Give 1 capsule ONCE daily for bone health	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				
Acetaminophen 5 mg tablets Give 2 tablets TWO times ONCE daily for pain relief	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				
Vitamin D 1,500 unit tablets Give 1 tablet ONCE daily for bone health	Breakfast	✓	✓	✓				
	Bedtime	✓	✓	✓				

SCHEDULES

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.



SUPPORT GROUPS

Support groups are groups of people with common experiences or concerns who encourage each other. People who share similar experiences can sometimes really understand how others feel and can have practical advice to share.



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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>