



# CHRONIC KIDNEY DISEASE

PARENT AND CAREGIVER RESOURCE

## PARENT AND CAREGIVER RESOURCE

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Kidney Disease is a **chronic disease** and **kidney function** may eventually get lower. **Chronic Kidney Disease** is also called **CKD**. The **Kidney Health Team** works with you and your child to delay the loss of kidney function as much as possible. The **medicines**, the eating and physical activity recommendations can all help slow down the **progression** of CKD.

As you and your family learn to live with kidney disease, **routines** and structure will help you adjust. Structure and routine make children feel secure and safe. Routines make it easier to take medicines as prescribed. If you don't have many routines in your family, you might want to try starting some. If you want to talk about this more, let us know and we can help.

As the parent or caregiver, you are in charge of managing changes as CKD progresses. Managing a chronic disease requires patience, flexibility and consistency. There are many factors that influence

your child's CKD. There is often a delicate interaction between all these factors and sometimes it takes time and patience to figure out the best changes to your child's **kidney health care plan**.

Managing these changes as your child's CKD changes is stressful. The Kidney Health Team is here to help you as the parent and caregiver to adjust and cope with these changes.

Dealing with ongoing changes is an absolute certainty when it comes to your child's CKD. Changes to medicines, foods and drinks are all normal parts of living with a chronic disease.

When the home life has more routine, it can be easier to stick to **schedules**. For example, medicines are more effective when they are taken as prescribed. Establishing patterns and schedules helps make the chronic disease part of everyday life.

Your child may feel that their life is controlled by

## CHRONIC KIDNEY DISEASE

their CKD. Whenever it is appropriate, get input from your teen about making changes in the routine that work for everyone. Being more active in our own health, gives people more control and, often, helps us make better choices.

### 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://kidneyschool.org/>

[http://www.youtube.com/watch?v=\\_VnTjWwuNcs&feature=related](http://www.youtube.com/watch?v=_VnTjWwuNcs&feature=related)

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

<http://kidneyweb.net/handouts.htm>

### WEB BASED RESOURCES HANDOUTS FOR KIDS

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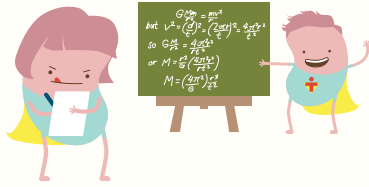
[http://www.youtube.com/watch?v=\\_VnTjWwuNcs&feature=related](http://www.youtube.com/watch?v=_VnTjWwuNcs&feature=related)

### HANDOUTS

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

## CHRONIC KIDNEY DISEASE GLOSSARY



### ACID

Acid is a substance our body uses for normal energy metabolism and good function of different tissues in the body. Foods we eat contain different amounts of acid. The body acid level is controlled by the kidneys.



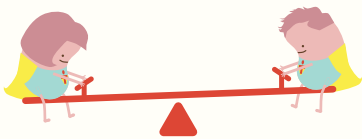
### ACTIVE VITAMIN D

Active vitamin D is the form of vitamin D that our body can use best. Active vitamin D is important for healthy bones because it has the strongest effect in the body to control calcium and phosphate levels. The kidneys control the amount of active vitamin D.



### ANEMIA

Anemia is when the amount of red blood cells in the body is too low. Red blood cells are important because they bring oxygen around the body, for the body to turn nutrients from food into energy.



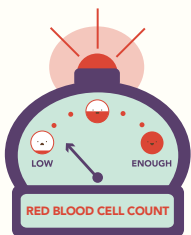
### BALANCE

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

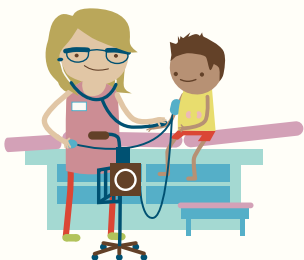
Blood moves or circulates around the body in blood vessels called arteries and veins. Blood carries energy nutrients, oxygen and other important substances to help our tissues and organs work well.



### BLOOD COUNT

Blood count is a test used to measure the amount of blood cells in our body, like red blood cells and white blood cells. The test is done by taking a sample of our blood and looking at it in a lab under a microscope.

## CHRONIC KIDNEY DISEASE



### BLOOD PRESSURE

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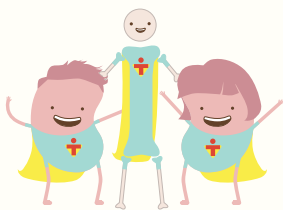
Blood pressure keeps our heart full enough so it can pump blood to our whole body. Our body needs the right blood pressure so it can push blood to our brain, kidneys, muscles and other tissues and organs in our body. The kidneys help control the blood pressure in our body.



### BLOOD TEST

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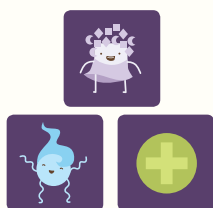
Blood tests can check how well our body is working, whether we have enough or too much of certain vitamins and minerals and whether we might have an infection. A blood test is done by taking a small sample of our blood and testing it in a lab.



### BONES

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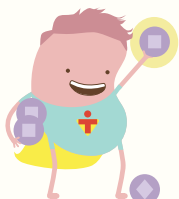
Bones are made of calcium, phosphate and other substances, and form our body skeleton. Healthy bones need enough nutrients from the food we eat, enough physical activity, and the right vitamins and hormones in our body. The kidneys are important for keeping bones healthy.



### BUILDING BLOCKS

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“Building blocks” is a way to explain how the body uses different substances together to make our body tissues and organs work, become stronger and healthier. The building blocks for each body system are different. For example, the bones use the calcium, phosphate and vitamin D building blocks. Muscles need the right amount of protein, potassium, calcium and energy building blocks.



### CALCIUM

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Calcium is a building block mineral our body needs. We get it from food. It is important for strong bones and many other things in our body. The right amount of calcium in the body is controlled by what we eat, vitamins, hormones and the kidneys.

# 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.

# GFR

## GFR

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GFR stands for glomerular filtration rate. GFR is an important way to tell how well the kidneys are cleaning the blood. If the GFR is lower it means that the kidney function is lower.



## GFR TEST

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GFR test(s) is a test for measuring the GFR. It is usually done by giving a blood injection of a substance into the body that the kidneys can clean out of the blood. Blood tests are checked to see how much is left after some time. We know the amount of GFR by how fast the blood level of the substance we injected drops.

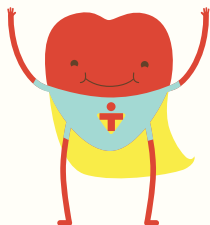
## CHRONIC KIDNEY DISEASE



### GREEN FOODS

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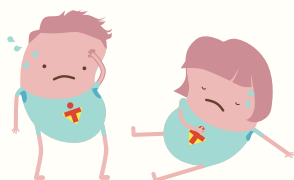
Green Foods are Whole Foods. Whole Foods give our bodies the nutrients we need to stay healthy. Whole Foods are from plants and animals and home-cooked from raw ingredients. Choose Whole Foods First!



### HEART

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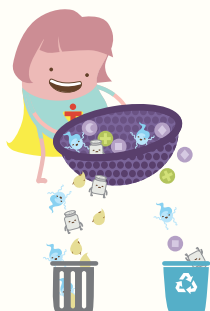
The heart is the organ in the upper left side of our chest and is connected to blood vessels (arteries and veins). With every heart beat, the heart fills with blood that is pumped out to all the body tissues and organs. The work of every heart beat is related to the blood pressure. The kidneys help control blood pressure.



### KIDNEY FAILURE

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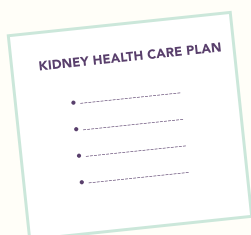
Kidney failure is when the kidney function is lower than normal. It means that the kidney cannot clean the blood as well as usual. Kidney failure can be checked with blood tests like creatinine or with a GFR test. Kidney failure can happen quickly or slowly over time. Sometimes kidney failure is related to permanent kidney damage – we call that CKD (chronic kidney disease). If the kidney failure is causing very low kidney function, kidney function can be replaced with treatments like dialysis.



### KIDNEY FUNCTION

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The kidneys do many things in our body. Some kidney functions include: cleaning the body waste from blood, recycling things the body needs, balancing salt, water and minerals, and adjusting levels of vitamins and hormones for important body functions. Some body functions are blood pressure, bone health and making blood.



### KIDNEY HEALTH CARE PLAN

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Kidney health care plan is a written plan used to help you and your family take care of your kidney health. This plan can include information about eating, exercises, kidney tests, and medicines. The Kidney Health Team will work with you to make a plan for your kidney health.



### KIDNEY HEALTH CLINIC

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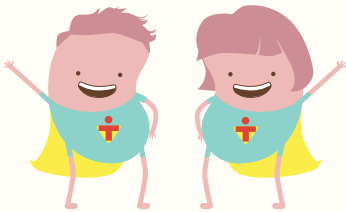
Kidney Health Clinic is a place where doctors, nurses and other members of the Kidney Health Team can see you to check on your kidney health and how you are doing.



### 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.

### METABOLISM

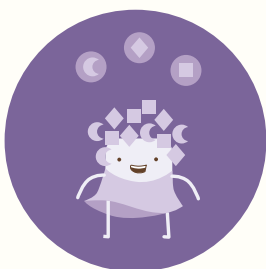
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## METABOLISM

Metabolism is how all the different chemical substances in the body work together. Sometimes it is about how the body uses energy, builds tissues up or breaks them down. When metabolism is not normal, it is often related to a disease. Different tests can tell us about our metabolism.



## CHRONIC KIDNEY DISEASE



### MINERAL(S)

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Minerals are important building blocks our body needs to stay healthy. There are many different substances that we call minerals, like calcium, phosphate and potassium. Minerals get into our body in our food. Our kidneys help to maintain or keep the right amount of minerals in our body.



### 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.



### MUSCLE(S)

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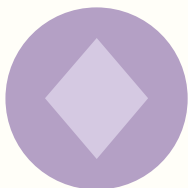
Our muscles help our body move and work. Some muscles we can control, like the muscles in our legs that help us walk. Other muscles like our heart keep on working - beating - all the time without us even thinking about it.



### NUTRIENTS AND NUTRITION

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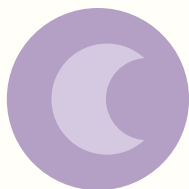
Nutrition is about getting the nutrients our body needs for health and growth. Nutrients are all the different types of ingredients our body needs for energy and building blocks. We usually get nutrients through food. When nutrition is good, our body can grow well and be healthy.



### POTASSIUM

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Potassium is a building block mineral our body needs. We get it from food. It is important for our muscles and nerves and many other things in our body. The right amount of potassium in the body is controlled by what we eat, vitamins, hormones and the kidneys. When there is kidney failure, potassium can build up and too much potassium can be dangerous.



### PHOSPHATE

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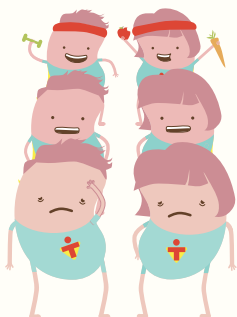
Phosphate is a building block mineral our body needs. We get it from food. It is important for strong bones and many other things in our body. The right amount of phosphate in the body is controlled by what we eat, vitamins, hormones and the kidneys. When there is kidney failure, sometimes we need to limit foods with phosphate or take binders to keep our bones healthy.



### PROCESSED FOODS

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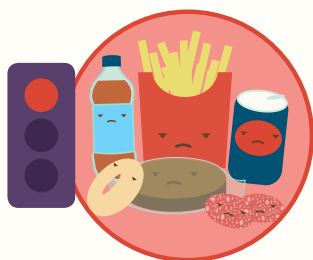
Processed foods are foods that started as whole foods, but got changed in a factory to make something else. Some important nutrients get lost when food is processed. Extra sugar or salt or chemicals are added to make it taste better or look different.



### PROGRESSION

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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.



### RED FOODS

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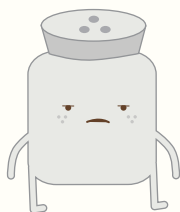
Red Foods are foods to avoid. Red Foods are highly processed and are often called Junk Foods. Red Foods are missing most important nutrients. Most Red Foods have lots of added sugar, salt, preservatives and artificial ingredients like food colouring and flavourings. These ingredients do not help our body.



### ROUTINE

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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.



## SALT

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Salt is made up of two substances called sodium and chloride. It is something we taste in our food. Sodium in salt is important to control the amount of fluid and blood pressure in our body: when we have more sodium, we feel thirsty and too much sodium can make us swollen. If you are losing salt and water, like with stomach flu, you get dehydrated. Our kidneys help balance salt and water in our body.

**ur·e·mi·a** noun

**Definition of UREMIA:**  
the illness caused by very low kidney function and buildup of waste in the body.

## UREMIA

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An illness caused by very low kidney function and a build up of waste in the body. Uremia can make people feel nauseated and make them very tired.



## 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.



## VITAMIN D

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Vitamin D is a vitamin that helps our body absorb and use calcium and phosphate from foods we eat or drink. Vitamin D can be made by our skin with the help of sunshine. Sometimes we need to take extra Vitamin D. The kidneys change Vitamin D into Active Vitamin D, to help build strong bones.



## VITAMIN(S)

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Vitamins are important building blocks our body needs to stay healthy. Every vitamin has a different job to do in our body. Whole foods are a great source of vitamins.



## WASTE

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Waste is made when our body is using up the building blocks needed for growth and breaking down nutrients in food. Our body gets rid of this waste in our bowel movements and urine when we go to the bathroom. There is waste in our blood and it is mostly cleaned out by the kidneys and goes out in the urine.



### **WATER**

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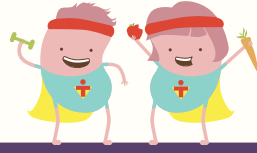
Water is the liquid that we drink. Our bodies are made of mostly water. The amount of salt in our body affects the amount water we have. The kidneys are very important to keep the amount of salt and water for our body in balance.



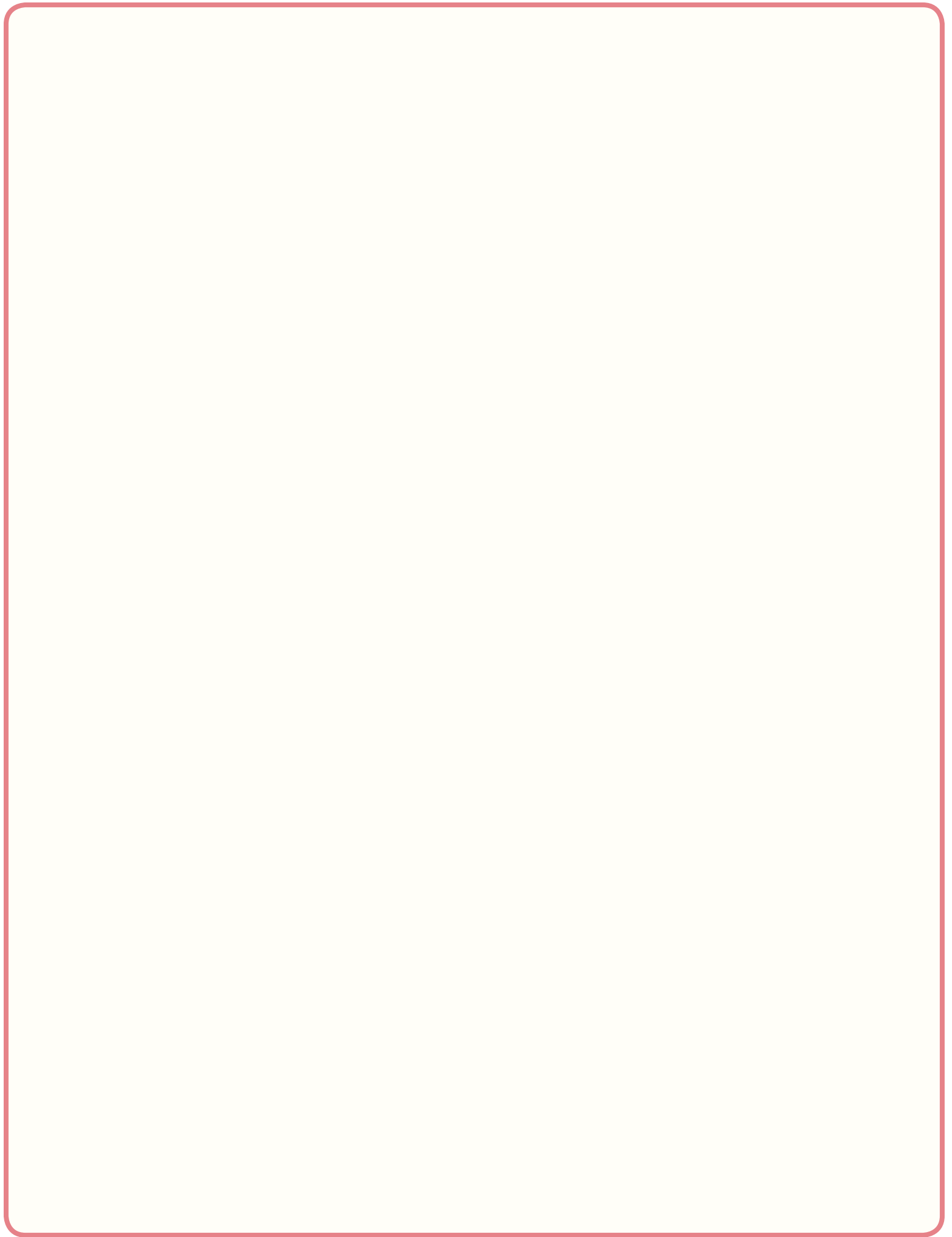
### **YELLOW FOODS**

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Yellow Foods are foods we should only eat sometimes. Yellow Foods are usually processed with added salt, added sugar, preservatives and artificial ingredients. Because they are processed, some of the important nutrients have been removed. Yellow Foods give our bodies some of the nutrients we need.

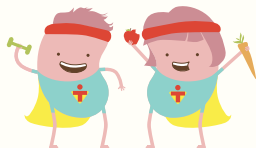


## NOTES





**HEALTHY KIDNEYS**



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>