

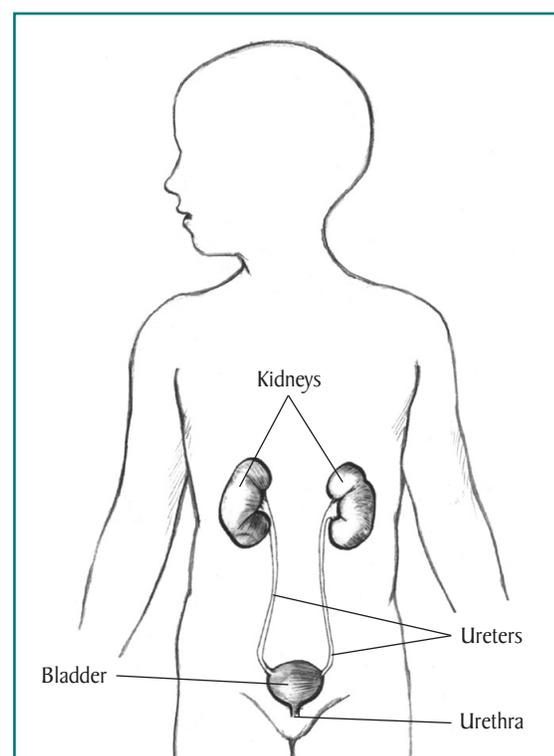
Treatment Methods for Kidney Failure in Children

What are the kidneys and what do they do?

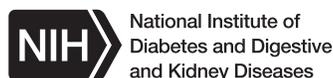
The kidneys are two bean-shaped organs, each about the size of a fist. They are located just below the rib cage, one on each side of the spine. Every day, the two kidneys filter about 120 to 150 quarts of blood to produce about 1 to 2 quarts of urine, composed of wastes and extra fluid. Children produce less urine than adults and the amount produced depends on their age. The kidneys work around the clock; a person does not control what they do. Ureters are the thin tubes of muscle—one on each side of the bladder—that carry urine from each of the kidneys to the bladder. The bladder stores urine until the person finds an appropriate time and place to urinate.

Kidneys work at the microscopic level. The kidney is not one large filter. Each kidney is made up of about a million filtering units called nephrons. Each nephron filters a small amount of blood. The nephron includes a filter, called the glomerulus, and a tubule. The nephrons work through a two-step process. The glomerulus lets fluid and waste products pass through it; however, it prevents blood cells and large molecules, mostly proteins, from passing. The filtered fluid then passes through the tubule, which sends needed minerals back to the bloodstream and removes wastes. The final product becomes urine.

The kidneys also control the level of minerals such as sodium, phosphorus, and potassium in the body, and they produce an important hormone to prevent anemia. Anemia is a condition in which the number of red blood cells is less than normal, resulting in less oxygen carried to the body's cells.



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What is kidney failure and how is it treated in children?

Kidney failure—described as end-stage kidney disease or ESRD when treated with a kidney transplant or blood-filtering treatments called dialysis—means the kidneys no longer work well enough to do their job. In most cases, kidney failure in children is treated with a kidney transplant. Though some children receive a kidney transplant before their kidneys fail completely, many children begin with dialysis to stay healthy until they can have a transplant.

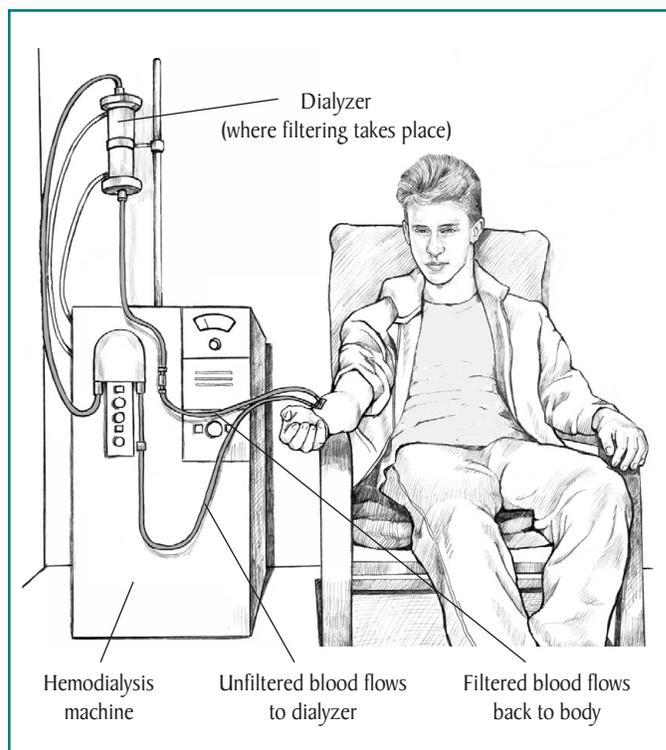
Dialysis is the process of filtering wastes and extra fluid from the body by means other than the kidneys. Sometimes, a transplanted kidney may stop working, and the child may need to return to dialysis. Transplantation may be delayed if a matching kidney is not available or if the child has an infectious disease or an active kidney disease that has progressed rapidly.

What are the types of dialysis?

Hemodialysis and peritoneal dialysis are the two types of dialysis.

Hemodialysis

Hemodialysis uses a special filter called a dialyzer to remove wastes and extra fluid from the blood. The dialyzer is connected to a hemodialysis machine. Blood is pumped through a tube into the dialyzer to filter out the wastes and extra fluid. The filtered blood then flows through another tube back into the body. The hemodialysis machine monitors the process to keep blood moving at a safe pace. Hemodialysis helps control blood pressure and helps the body maintain the proper balance of important minerals, such as potassium, sodium, calcium, and bicarbonate.



Hemodialysis uses a special filter called a dialyzer to remove wastes and extra fluid from the blood.

Hemodialysis usually takes place in a dialysis center three times a week; however, a health care provider may recommend more frequent dialysis for smaller children. Each treatment usually lasts from 3 to 5 hours. During treatment, the child can do homework, read, write, sleep, talk, or watch TV.

Some dialysis centers teach parents or guardians how to perform their child's hemodialysis at home. Having treatments at home allows for longer or more frequent dialysis, which comes closer to replacing the steady work healthy kidneys do.

- Daily home hemodialysis is done 5 to 7 days per week for 2 to 3 hours at a time.
- Another option is to perform hemodialysis at home 3 to 6 nights a week while the child sleeps.
- Though home hemodialysis allows more flexibility in scheduling and may have better results, learning how to perform the procedure often takes 3 to 8 weeks.

For hemodialysis, a surgeon creates an access to the bloodstream, called a vascular access, several months before the first treatment. A surgeon may create a vascular access at an outpatient center, or the child may need to stay overnight in the hospital. When receiving hemodialysis treatments, a child may have problems with the vascular access, such as

- infection
- poor blood flow
- blockage from a blood clot

These problems can keep treatments from working, and the child may need to undergo more than one surgery for the access to work properly. Read more in *Vascular Access for Hemodialysis* at www.kidney.niddk.nih.gov.

Rapid changes in the body's fluid and mineral balance during treatment may cause other problems with hemodialysis treatments. Muscle cramps and hypotension—a sudden drop in blood pressure—are two common side effects. Hypotension can make a child feel weak, dizzy, or nauseous. A health care provider can treat these problems with adjustments to the dialysis solution prescription and the speed at which blood flows through the dialyzer.

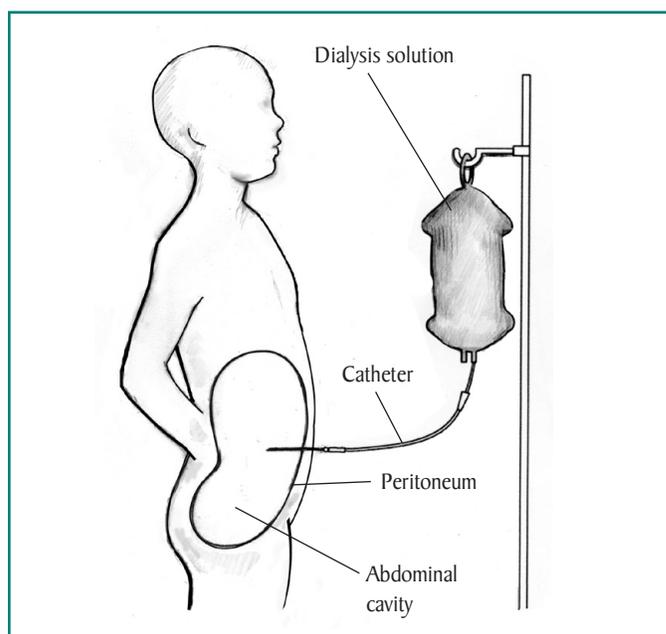
Most children need a few months to adjust to hemodialysis. A health care provider can often quickly and easily treat side effects, so a parent or guardian should always report side effects to a member of the health care team. A parent or guardian can help a child prevent many side effects by making sure the child maintains a proper diet, limits liquid intake, and takes all medications as directed. See “Eating, Diet, and Nutrition” for more information on how the right food choices can help.

Read more in *Treatment Methods for Kidney Failure: Hemodialysis* at www.kidney.niddk.nih.gov.

Peritoneal Dialysis

Peritoneal dialysis uses the lining of the abdominal cavity—the space in the body that holds organs such as the stomach, intestines, and liver—to filter the blood. The lining is called the peritoneum. A kind of salty water called dialysis solution is emptied from a plastic bag through a catheter—a thin, flexible tube—into the abdominal cavity. While it is inside, the dialysis solution soaks up wastes and extra fluid from the body. After a few hours, the used dialysis solution is drained into another bag, removing the wastes and extra fluid from the body. The abdomen is filled with fluid all day and all night, so the filtering process never stops. The process of draining and refilling, called an exchange, takes about 30 minutes.

Before peritoneal dialysis begins, a surgeon places a catheter into the child's abdomen. The catheter insertion may be done as an outpatient procedure, or the child may need to stay overnight in the hospital. The catheter tends to work better if the insertion site, also known as the exit site, has adequate time to heal—usually 10 to 20 days. The catheter may have one or two cuffs that the abdominal tissue grows around to secure it in place.



Peritoneal dialysis uses the lining of the abdominal cavity to filter the blood.

Two types of peritoneal dialysis are available for children:

- **Continuous ambulatory peritoneal dialysis (CAPD).** CAPD requires no machine and can be done in any clean, well-lit place. With CAPD, the blood is always being filtered. The dialysis solution stays in the abdomen for 4 to 6 hours or more between exchanges, called dwell time. Most children change the dialysis solution at least four times a day and sleep with solution in their abdominal cavity at night. With CAPD, it is not necessary to wake up and perform dialysis tasks during the night.
- **Continuous cycling peritoneal dialysis (CCPD).** CCPD uses a machine called a cyclor to fill and empty the abdomen three to five times during the night while a child sleeps. In the morning, the abdomen is filled with dialysis solution for a dwell time that lasts the entire day. Sometimes, an additional exchange can be done in the middle of the afternoon without the cyclor to increase the amount of waste removed and to reduce the amount of fluid left behind in the body.

Both types of peritoneal dialysis are usually performed at home, after a short training period. Parents or guardians and the child work with a dialysis nurse for 1 to 2 weeks learning how to do manual exchanges for CAPD without allowing bacteria to enter the catheter. Those doing CCPD learn how to prepare the cyclor, connect the bags of dialysis solution, and place the drain tube. Young children will need help with the exchanges or setting up the cyclor. Older children can do it themselves.

The most common problem with peritoneal dialysis is development of peritonitis, a serious infection of the peritoneum. This infection can occur if the exit site becomes infected or if contamination occurs as the catheter is connected to, or disconnected from, the bags of dialysis solution. Peritonitis is treated with bacteria-fighting medications called antibiotics.

To prevent peritonitis, those performing peritoneal dialysis tasks should wear a surgical mask, follow procedures exactly, and learn to recognize the early signs of peritonitis, including

- fever
- nausea or vomiting
- redness or pain around the catheter insertion site
- unusual color or cloudiness in used dialysis solution
- a catheter cuff that has been pushed out of the body

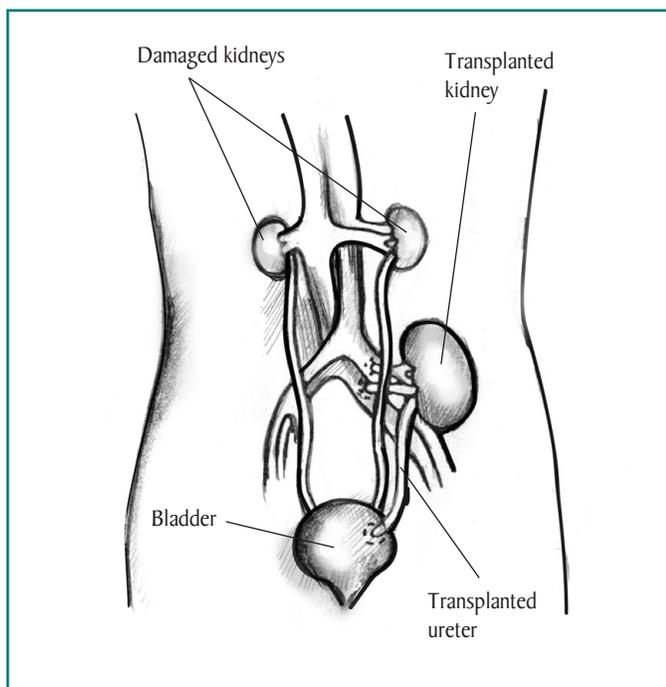
These signs should be reported to the child's health care provider immediately, so treatment can begin promptly.

Read more in *Treatment Methods for Kidney Failure: Peritoneal Dialysis* at www.kidney.niddk.nih.gov.

What is kidney transplantation?

Kidney transplantation is surgery to place a healthy kidney from someone who has just died or a living donor, usually a family member, into a person's body to take over the job of the failing kidney. Once kidneys fail because of chronic kidney disease (CKD), function cannot be restored, so transplantation is the closest thing to a cure. Children with a transplant will need to take medications every day to prevent their body from rejecting the new kidney and get regular checkups to make sure the new kidney is accepted and functioning properly.

To receive a donor kidney, a child first undergoes a thorough medical evaluation at a transplant center.



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Deceased Donor Kidneys

If the medical evaluation shows that the child does not have a condition that would prevent a successful transplant, the transplant coordinator places the child on a waiting list.

Transplant coordinators register those needing a deceased donor organ with the United Network for Organ Sharing (UNOS), which maintains a centralized computer network linking all regional organ procurement organizations (OPOs) and transplant centers. A child can be registered with multiple transplant centers; most centers require a separate medical evaluation.

The length of time a child has to wait for a transplant depends on many things; however, it is determined primarily by how good the match is between the child and the donor. A child's place on the list depends on the following:

- tissue typing—a blood test that checks six antigens, or proteins, that make each person different. Tissue typing lets the transplant surgeon know how many antigens the donor shares with the recipient.
- blood type.
- length of time on the waiting list.
- age of child waiting.
- blood antibody levels, which show how active the immune system is at the current time, a factor that can increase the risk of rejection. The immune system normally protects people from infection by identifying and destroying bacteria, viruses, and other potentially harmful foreign substances.

When a kidney becomes available, the OPO reports to UNOS, and a central computer generates a ranked list of compatible recipients. The transplant center keeps each child's updated contact and health status information, so the child can be found immediately when a kidney becomes available.

Living Donor Kidneys

About half of the kidneys transplanted into children are from living donors, often a parent, family member, or family friend.¹ Potential donors need to be tested for matching factors and to make sure that donating a kidney will not endanger their health.

A kidney from a living donor often has advantages over a kidney from a deceased donor because

- a kidney from a parent is more likely to be a better tissue match than a kidney from someone who is not related to the child
- living donation allows for greater preparation; for example, the operation can be scheduled in advance
- the kidney does not have to be transported from one site to another, so it may be in better condition

Read more in *Treatment Methods for Kidney Failure: Transplantation* at www.kidney.niddk.nih.gov.

Preemptive Transplantation

Preemptive transplantation is when a child receives a donated kidney before dialysis is needed. Some studies indicate that preemptive transplantation reduces the chances of the body rejecting the new kidney and improves the chances of the new kidney functioning for a long time. Other studies show little or no advantage to preemptive transplants, although some families may feel that avoiding dialysis is itself an advantage.

What are the possible complications for children with a kidney transplant?

Children with a kidney transplant are at risk for complications such as organ rejection, infection, and certain types of cancer. They may also need treatment to increase their growth rate.

Organ Rejection

The body's immune system can attack transplanted organs. This reaction is known as rejection. Children with a kidney transplant need to take immunosuppressive medications to prevent the body from making antibodies and rejecting the kidney. Many children have a hard time following the treatment regimen. Health care providers use the term nonadherence to describe the failure or refusal to take prescribed medications or follow a health care provider's directions. Adherence can be improved with a combination of health education, motivational techniques, and behavioral skill methods. Strategies need to be tailored to each child and the child's family. The health care provider should

- teach the child about the condition and treatment regimen
- talk with the child to learn about the child's wishes, beliefs, and feelings to find ways to improve motivation
- suggest methods for remembering to take medications, such as a calendar, a pillbox, or text message reminders

¹Transplants by donor type, U.S. transplants performed: January 1, 1988–December 31, 2012, for organ = kidney, format = portrait, based on OPTN data updated as of March 8, 2013. Organ Procurement and Transplantation Network website. <http://optn.transplant.hrsa.gov/latestData/step2.asp?> Accessed October 18, 2013.

Infection

Immunosuppressive medications can leave children vulnerable to infections and can also prevent the body from responding to vaccines. While children should get the standard vaccines as well as vaccines against influenza and pneumonia prior to transplantation, they may need to wait several months after the transplant before they get any additional vaccines. Children who take immunosuppressive medications should not receive vaccines containing live viruses, such as the

- oral polio vaccine
- measles, mumps, and rubella (MMR) vaccine
- varicella or chicken pox vaccine

Preventing infections is important for keeping children healthy after the transplant. To help prevent infections, parents or guardians should have their children

- avoid contact with people who are ill
- wash their hands often
- avoid raw or undercooked meats
- wear gloves when gardening or working outdoors
- avoid caring for pets
- report any signs or symptoms to the health care team right away

Cancer

Over a long period of time, children taking immunosuppressive medications may develop some forms of cancer. Cancer most often develops in the skin or lymph cells, part of the body's immune system. The incidence of cancer in pediatric transplant recipients is lower than in adults, with the risk being about 17 percent within 25 years of receiving the transplant.²

Growth Rate

Depending on their age at the time of the transplant, how well the transplanted kidney is working, and medication dosing, children may have an increase in growth after receiving a transplant, though they are typically shorter than average height. Children younger than 4 years old have the best growth rate after transplantation.² However, high doses of immunosuppressive medications can slow a child's growth and development after a transplant. Decreasing immunosuppressive medication dosing and giving the child growth hormone can improve growth rate.

What are the complications of kidney failure and how are they treated?

Children with kidney failure may also need treatment for complications such as anemia, bone problems and growth failure, and infection. These complications are caused by the inability of the damaged kidneys to make red blood cells, balance nutrients needed for strong bones and growth, or filter wastes and extra fluid from the blood.

Anemia

Damaged kidneys do not make enough of a hormone called erythropoietin (EPO), which stimulates the bone marrow to produce red blood cells. Anemia is common in children with kidney disease and causes them to tire easily and look pale. Anemia may also contribute to heart problems. A synthetic form of EPO injected under the skin one or more times a week can treat anemia caused by damaged kidneys.

Read more in *Anemia in Kidney Disease and Dialysis* at www.kidney.niddk.nih.gov.

²Van Heurn E, de Vries EE. Kidney transplantation and donation in children. *Pediatric Surgery International*. 2009;25:385–393.

Bone Problems and Growth Failure

The kidneys help bones stay healthy by balancing phosphorus and calcium levels in the blood. When the kidneys stop working, phosphorus levels in the blood can rise and interfere with bone formation and normal growth. When phosphorus levels become too high, a health care provider may prescribe medications to decrease blood phosphorus levels and increase blood calcium levels.

A health care provider may recommend dietary changes and food supplements or growth hormone injections to treat growth failure in children.

Read more about growth failure in *Growth Failure in Children with Kidney Disease* at www.kidney.niddk.nih.gov.

Infection

The wastes and toxins that build up in the bloodstream of children with kidney disease can weaken the immune system, making children vulnerable to certain infections and diseases. Vaccinations can help prevent certain infections, which is particularly important for children with a weakened immune system. Children with kidney failure should receive the standard vaccinations recommended for all children, as well as vaccinations to prevent influenza and pneumonia.

What are the challenges of kidney failure for children and their families?

The challenges of kidney failure for children include physical effects from the loss of kidney function and emotional effects due to their illness. Physical effects of kidney failure can include

- extreme fatigue
- weak bones
- nerve damage
- sleep problems
- growth failure

The buildup of wastes in the body can slow down nerve and brain function, resulting in trouble concentrating and slow language and motor skill development, often causing children to fall behind in school.

Emotional effects of kidney failure can include depression and feelings of isolation, which is especially a problem for children, who place great importance on making friends and fitting in. Children with kidney failure may need individualized plans to help them become active, productive, well-adjusted adults.

The challenges for families caring for a child with kidney failure can include understanding treatment options, scheduling and performing dialysis, and learning how to keep the child as healthy as possible. Family members should feel comfortable talking to any member of their child's health care team about their concerns and questions. Working closely with the health care team can make life easier for children with kidney failure and for their families.

Read more in *Facing the Challenges of Chronic Kidney Disease in Children* at www.kidney.niddk.nih.gov.

Who is on the health care team for children with kidney failure?

The following skilled professionals may be on a child's health care team:

- pediatrician
- nephrologist
- dialysis nurse
- transplant coordinator
- transplant surgeon
- social worker
- mental health professional
- financial counselor
- dietitian

Parents or guardians, however, are the most important members of a child's team. They may need to speak for the child or ask questions when instructions are not clear. Knowing the roles of the different team members can help parents or guardians ask the right questions and best contribute to the child's care.

Pediatrician

A pediatrician is a doctor who treats children. A child's pediatrician is likely to be the first to recognize a kidney problem—either during a routine physical exam or during a sick visit. Depending on how well the kidneys are working, the pediatrician may decide to monitor the child or refer the child to a specialist. The pediatrician should talk with any specialists who become involved. A consultation with a specialist should occur soon after CKD is diagnosed, even if dialysis and transplantation are still a long way off.

Nephrologist

A nephrologist is a doctor who treats kidney diseases and kidney failure. A child should see a pediatric nephrologist if possible because they are specially trained to take care of kidney problems in children. In many parts of the country, pediatric nephrologists are in short supply, so the child may need to travel. If traveling is not possible, some nephrologists who treat adults can also treat children in consultation with a pediatric nephrologist.

The nephrologist may prescribe treatments to slow disease progression and will determine when referral to a dialysis clinic or transplant center is appropriate.

Dialysis Nurse

If the child needs dialysis, a nurse with special training will make sure all procedures are followed carefully:

- For peritoneal dialysis, the dialysis nurse will train the parents or guardians so they feel comfortable performing exchanges at home.
- For hemodialysis in a clinic, the dialysis nurse will make sure all needles are placed correctly and watch for any problems.
- The dialysis nurse can discuss the advantages and disadvantages of the different types of dialysis and explain how well the treatments are working.

Transplant Coordinator

When preparing for a transplant, children and their families work with a coordinator at a transplant center, who serves as their main contact. The coordinator

- schedules any required exams and procedures
- ensures the child's medical information is complete
- places the child on the UNOS national waiting list
- makes sure every member of the child's health care team has all of the necessary information and paperwork

Transplant Surgeon

The transplant surgeon performs the kidney transplant and monitors a child's health before the surgery. Children waiting for a transplant need to stay as healthy as possible. After the surgery, the transplant surgeon will make sure the new kidney is working well.

Social Worker

Every dialysis clinic and transplant center has a social worker who can help families locate services such as transportation and family counseling. The social worker can provide information about

- finding support groups in the community
- helping a child with a chronic illness rejoin school activities
- reducing the stress of caring for a child with a chronic illness

The social worker can also help families submit applications for Medicare and Medicaid. Medicare is a program that helps people older than 65 and people with disabilities, including people of any age with kidney failure, pay for medical care. Medicaid is a health care program for certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law.

Mental Health Professional

A mental health professional, such as a psychologist, can help children with CKD find useful ways to deal with the emotional turmoil caused by having a chronic illness. Some child psychologists specialize in helping children with disabilities and medical problems rejoin school activities. They may be able to suggest ideas that reinforce adherence with taking medication and following the health care provider's instructions.

Family members may also find that counseling helps them handle the conflicts and stresses they face. Many couples report increased tension in their marriage when their child has a serious illness such as CKD. Siblings may resent the amount of attention given to their sibling with CKD and feel guilty about having bad thoughts about their sibling.

Financial Counselor

A financial counselor can help families meet the financial obligations that chronic illness creates. Medical bills can strain family finances; in some cases, a parent or guardian may need to stop working to care for a child full time.

Read more in *Financial Help for Treatment of Kidney Failure* at www.kidney.niddk.nih.gov.

Dietitian

Proper nutrition is extremely important for children with CKD. Every dialysis clinic has a dietitian to help people understand how the food they eat affects their health. The dietitian

- helps develop meal plans to fit a child's restricted diet
- provides information about possible nutritional deficiencies caused by kidney disease
- recommends special dietary supplements or formulas to improve the child's nutrition
- provides recipes and recommends cookbooks appropriate for people with kidney disease

Following the restrictions of a kidney disease diet might be hard at first; however, making tasty and satisfying meals is possible with just a little creativity.

Eating, Diet, and Nutrition

For children with CKD, learning about nutrition is vital because their diet can affect how well their kidneys work. Parents or guardians should always consult with their child's health care team before making any dietary changes. Staying healthy with CKD requires paying close attention to the following elements of a diet:

■ **Protein.** Children with CKD should eat enough protein for growth while limiting high protein intake. Too much protein can put an extra burden on the kidneys and cause kidney function to decline faster. Protein needs increase when a child is on dialysis because the dialysis process removes protein from the child's blood. The health care team recommends the amount of protein needed for the child. Foods with protein include

- eggs
- milk
- cheese
- chicken
- fish
- red meats
- beans
- yogurt
- cottage cheese

■ **Sodium.** The amount of sodium children need depends on the stage of their kidney disease, their age, and sometimes other factors. The health care team may recommend limiting or adding sodium and salt to the diet. Foods high in sodium include

- canned foods
- some frozen foods
- most processed foods
- some snack foods, such as chips and crackers

■ **Potassium.** Potassium levels need to stay in the normal range for children with CKD, because too little or too much potassium can cause heart and muscle problems. Children may need to stay away from some fruits and vegetables or reduce the number of servings and portion sizes to make sure they do not take in too much potassium. The health care team recommends the amount of potassium a child needs. Low-potassium fruits and vegetables include

- apples
- cranberries
- strawberries
- blueberries
- raspberries
- pineapple
- cabbage
- boiled cauliflower
- mustard greens
- uncooked broccoli

High-potassium fruits and vegetables include

- oranges
- melons
- apricots
- bananas
- potatoes
- tomatoes
- sweet potatoes
- cooked spinach
- cooked broccoli

■ **Phosphorus.** Children with CKD need to control the level of phosphorus in their blood because too much phosphorus pulls calcium from the bones, making them weaker and more likely to break. Too much phosphorus also can cause itchy skin and red eyes. As CKD progresses, a child may need to take a phosphate binder with meals to lower the concentration of phosphorus in the blood. Phosphorus is found in high-protein foods. Foods with low levels of phosphorus include

- liquid nondairy creamer
- green beans
- popcorn
- unprocessed meats from a butcher
- lemon-lime soda
- root beer
- powdered iced tea and lemonade mixes
- rice and corn cereals
- egg white
- sorbet

■ **Fluids.** Early in CKD, a child’s damaged kidneys may produce either too much or too little urine, which can lead to swelling or dehydration. As CKD progresses, children may need to limit fluid intake. The health care provider will tell the child and parents or guardians the goal for fluid intake.

Read more in *Nutrition for Chronic Kidney Disease in Children* and *Kidney Failure: Eat Right to Feel Right on Hemodialysis* at www.kidney.niddk.nih.gov.

Points to Remember

- Kidney failure—described as end-stage kidney disease or ESRD when treated with a kidney transplant or blood-filtering treatments called dialysis—means the kidneys no longer work well enough to do their job.
- In most cases, kidney failure in children is treated with a kidney transplant. Though some children receive a kidney transplant before their kidneys fail completely, many children begin with dialysis to stay healthy until they can have a transplant.
- Dialysis is the process of filtering wastes and extra fluid from the body by means other than the kidneys. Hemodialysis and peritoneal dialysis are the two types of dialysis.
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- Kidney transplantation is surgery to place a healthy kidney from someone who has just died or a living donor, usually a family member, into a person’s body to take over the job of the failing kidney.
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- The challenges of kidney failure for children include physical effects from the loss of kidney function and emotional effects due to their illness.
- The challenges for families caring for a child with kidney failure can include understanding treatment options, scheduling and performing dialysis, and learning how to keep the child as healthy as possible.
- The following skilled professionals may be on a child’s health care team:
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 - nephrologist
 - dialysis nurse
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 - social worker
 - mental health professional
 - financial counselor
 - dietitian
- Parents or guardians, however, are the most important members of a child’s team.
- For children with chronic kidney disease (CKD), learning about nutrition is vital because their diet can affect how well their kidneys work. Parents or guardians should always consult with their child’s health care team before making any dietary changes.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports research to help people with kidney diseases, including children. The NIDDK, in collaboration with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and the National Heart, Lung, and Blood Institute, funded the formation of a cooperative agreement between two Clinical Coordinating Centers and a Data Coordinating Center to conduct a prospective epidemiological study of children with CKD. The primary goals of the Chronic Kidney Disease in Children Prospective Cohort Study (CKiD) are to

- determine the risk factors for decline in kidney function
- define how a progressive decline in kidney function affects neurocognitive function and behavior
- determine risk factors for cardiovascular disease
- assess growth failure and its associated morbidity

More information about the CKiD, funded under National Institutes of Health (NIH) clinical trial number NCT00327860, can be found at www.statepi.jhsph.edu/ckid.

Clinical trials are research studies involving people. Clinical trials look at safe and effective new ways to prevent, detect, or treat disease. Researchers also use clinical trials to look at other aspects of care, such as improving the quality of life for people with chronic illnesses. To learn more about clinical trials, why they matter, and how to participate, visit the NIH Clinical Research Trials and You website at www.nih.gov/health/clinicaltrials. For information about current studies, visit www.ClinicalTrials.gov.

For More Information

American Association of Kidney Patients
2701 North Rocky Point Drive, Suite 150
Tampa, FL 33607
Phone: 1-800-749-2257 or 813-636-8100
Fax: 813-636-8122
Email: info@aakp.org
Internet: www.aakp.org

American Kidney Fund
11921 Rockville Pike, Suite 300
Rockville, MD 20852
Phone: 1-866-300-2900
Email: helpline@kidneyfund.org
or patientservice@kidneyfund.org
Internet: www.kidneyfund.org

American Society of Pediatric Nephrology
3400 Research Forest Drive, Suite B-7
The Woodlands, TX 77381
Phone: 281-419-0052
Fax: 281-419-0082
Email: info@aspneph.com
Internet: www.aspneph.com

American Society of Transplantation
15000 Commerce Parkway, Suite C
Mt. Laurel, NJ 08054
Phone: 856-439-9986
Fax: 856-439-9982
Email: info@myAST.org
Internet: www.a-s-t.org

Life Options

c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Suite 200
Madison, WI 53719
Phone: 1-800-468-7777 or 608-833-8033
Fax: 608-833-8366
Internet: www.lifeoptions.org
www.kidneyschool.org

National Kidney Foundation

30 East 33rd Street
New York, NY 10016
Phone: 1-800-622-9010
or 212-889-2210
Fax: 212-689-9261
Internet: www.kidney.org

United Network for Organ Sharing

P.O. Box 2484
Richmond, VA 23218
Phone: 1-888-894-6361
or 804-782-4800
Fax: 804-782-4817
Internet: www.unos.org

Resources

American Society of Transplantation

Facts about Kidney Transplantation: Pediatric Patient Education Brochure

www.myast.org/sites/default/files/images/2_FACT%20ABOUT%20KIDNEYTRANSPLANTATION%20%20FINAL.pdf

National Kidney Foundation

Children with Chronic Kidney Disease: Tips for Parents

www.kidney.org/atoz/content/childckdtips.cfm

Family Focus newsletter

www.kidney.org/patients/pfc/backissues.cfm

Employers' Guide

www.kidney.org/atoz/content/employersguide.cfm

Nemours KidsHealth Website

When Your Child Has a Chronic Kidney Disease

www.kidshealth.org/parent/medical/kidney/chronic_kidney_disease.html

What's the Deal with Dialysis?

www.kidshealth.org/kid/feel_better/things/dialysis.html

Nephkids

Cyber-support group

www.cybernephrology.ualberta.ca/nephkids

United Network for Organ Sharing

Organ Transplants: What Every Kid Needs to Know

www.unos.org/docs/WEKNTK.pdf

U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services

*Medicare Coverage of Kidney Dialysis & Kidney
Transplant Services*

[www.medicare.gov/Publications/Pubs/pdf/
10128.pdf](http://www.medicare.gov/Publications/Pubs/pdf/10128.pdf)

U.S. Social Security Administration

Benefits for Children with Disabilities

www.socialsecurity.gov/pubs/EN-05-10026.pdf

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The National Kidney Disease Education Program (NKDEP) is an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, U.S. Department of Health and Human Services. The NKDEP aims to raise awareness of the seriousness of kidney disease, the importance of testing those at high risk, and the availability of treatment to prevent or slow kidney disease.

You may also find additional information about this topic by visiting MedlinePlus at www.medlineplus.gov.

This publication may contain information about medications and, when taken as prescribed, the conditions they treat. When prepared, this publication included the most current information available. For updates or for questions about any medications, contact the U.S. Food and Drug Administration toll-free at 1-888-INFO-FDA (1-888-463-6332) or visit www.fda.gov. Consult your health care provider for more information.

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