

**How can parents and other adults help children with chronic kidney disease in daily life?**

Parents and other adults can help children with CKD fit in at school, deal with low self-esteem, make friends, be physically active, and follow their treatment regimen. As children with CKD approach adulthood, they may need help with preparing to enter the workforce.

**Attending School**

School attendance is vital in helping children with CKD lead the best life possible. Many people are unaware of how CKD affects children. School administrators, teachers, and classmates should receive education and information about the effects of CKD.

Children with kidney failure may miss school each week because of dialysis and medical appointments. These absences can compound the learning problems many children with CKD face. Parents or guardians should make every effort to schedule treatments outside of school hours.

Every child is entitled to an appropriate education and directs school districts to provide special services to ensure children with disabilities can participate in regular classrooms to the fullest extent possible. Children with CKD may need

* tutoring
* vocational rehabilitation
* special accommodations

To receive special education services, children must be evaluated to see if they have a disability and must receive an Individualized Education Program—a written document that details the services each child will receive. Parents or guardians of children with CKD should talk with the school counselor about having their child evaluated.

**Dealing with Low Self-esteem**

Having a chronic illness can make a child feel depressed and powerless. Learning and growth problems may also contribute to low self-esteem. One way to help children feel empowered is to give them as much control and responsibility over their own care as possible:

* Children can learn more about their medications, including doses.
* Children on dialysis should be encouraged to take an active part in their treatments.
* Parents or guardians should allow children to participate in treatment decision making.

Urinary incontinence—the loss of bladder control, which results in the accidental loss of urine—is common in children with CKD. Urinary incontinence can be embarrassing for children and can make it harder to build relationships with their peers. However, several strategies and treatment options are available to help prevent urinary incontinence.

More information is provided in the NIDDK health topic, [Urinary Incontinence in Children](http://www.niddk.nih.gov/health-information/health-topics/urologic-disease/urinary-incontinence-in-children/Pages/facts.aspx).

**Making Friends**

Children with CKD may have trouble fitting in with children their own age because of their small stature or delayed mental development. For children who have had a transplant, the side effects—such as a full face, weight gain, acne, or facial hair—of some of the medications they take may make it harder to make friends and may also lower self-esteem. Participating in regular classroom and extracurricular activities may help children improve their social skills. Summer camps and recreational programs for children with special needs can be a good place to make new friends.

**Participating in Physical Activities and Sports**

Children with CKD should be encouraged to participate in physical activities, including exercise and sports. In general, exercise has physical and psychological benefits. Parents or guardians may feel protective of children with CKD; however, they should not try to limit activities unless instructed to by a health care provider. Some children may even need to be encouraged to get outside and play. Parents or guardians should talk with their child’s health care provider about the right activity level and appropriate sports for their child.

Children who have had a kidney transplant can compete in sports. Every year the Transplant Games, sponsored by the National Kidney Foundation, allow people with transplants to participate in friendly competition and show the world that transplantation provides a new lease on life and health.

**Following Treatment Regimens**

Children with CKD may need to take multiple medications, eat a specific diet, and follow their health care provider’s orders to help control their disease. 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

**Preparing to Enter the Work Force**

Young adults who have been treated for CKD during childhood have to overcome a number of barriers to prepare for a career and find a job. Completing the training required for employment takes more effort, and some people with CKD report that their small stature creates problems fitting into adult environments. Employers may have trouble understanding kidney problems and the accommodations that need to be made for people with CKD. The employment section of the U.S. Department of Labor’s Disability website offers a variety of resources for employers and job seekers about career planning, workplace accommodations, work incentive programs, and other related issues.

**Who can help families deal with issues related to chronic kidney disease in children?**

Many skilled professionals are available to ensure that children with CKD get the best possible care. The family may want to talk with a social worker, mental health professional, financial counselor, and dietitian. If a child reaches kidney failure, the medical staff at the dialysis center or transplantation clinic can provide help.

**Social Worker**

A social worker 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

**Mental Health Professional**

A mental health professional, such as a psychologist, can help children with CKD find ways to deal with the emotional turmoil caused by having a chronic illness. Some child psychologists also specialize in helping children with disabilities and medical problems rejoin school activities. They may also be able to suggest techniques 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.

**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 whites
  + 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.

**Points to Remember**

* Children with chronic kidney disease (CKD) may have a negative self-image and may have relationship problems with family members due to the stress of living with a chronic disease. The condition can lead to behavior problems and make participating in school and extracurricular activities more difficult.
* CKD can cause learning problems because the buildup of wastes in the body can slow down nerve and brain function. Children with CKD may have trouble concentrating and may develop language and motor skills more slowly than their peers.
* Parents and other adults can help children with CKD fit in at school, deal with low self-esteem, make friends, be physically active, and follow their treatment regimen. As children with CKD approach adulthood, they may need help with preparing to enter the workforce.
* School attendance is vital in helping children with CKD lead the best life possible.
* One way to help children feel empowered is to give them as much control and responsibility over their own care as possible:
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  + Children on dialysis should be encouraged to take an active part in their treatments.
  + Parents or guardians should allow children to participate in treatment decision making.
* Participating in regular classroom and extracurricular activities may help children improve their social skills. Summer camps and recreational programs for children with special needs can be a good place to make new friends.
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* Children with CKD may need to take multiple medications, eat a specific diet, and follow their health care provider’s orders to help control their disease. 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.
* Many skilled professionals are available to ensure that children with CKD get the best possible care. The family may want to talk with a social worker, mental health professional, financial counselor, and dietitian. If a child reaches kidney failure, the medical staff at the dialysis center or transplantation clinic can provide help.
* 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.

http://www.niddk.nih.gov/health-information/health-topics/kidney-disease/facing-the-challenges-of-chronic-kidney-disease-in-children/Pages/facts.aspx