



# School & Family Problems of Children With Kidney Failure

Serious and long-lasting conditions like kidney failure affect many parts of a child's life. Having kidney failure influences a child's self-image and relationships with peers and family. It can lead to behavior problems and make achieving goals more difficult. Being aware of these problems can help you recognize that your child may need some additional guidance or understanding at times.

## Areas Where Your Child May Need Help

Kidney disease can cause learning problems. The buildup of wastes in the body can hamper nerve and brain function. Your child may have problems concentrating and may develop language and motor skills more slowly than peers. The most severe problems occur when kidney disease is present early in infancy. Fortunately, transplantation can reverse most of these conditions. Adequate dialysis can also improve or correct these problems. If they receive appropriate treatment, most children with kidney disease can attend school and graduate from high school. Many go on to college or vocational school.

## Attending School

Having as normal a life as possible can help a child feel more like other children. Going to school is especially important. You are likely to encounter

many people who are unaware of how kidney disease affects a child, so you may need to inform teachers and classmates of some of the possible problems.

Children who have in-center hemodialysis or frequent medical appointments may miss several hours of school each week. These absences can compound the learning problems that many children with kidney failure face. You should make every effort to schedule your child's treatments around the school schedule.

The Individuals with Disabilities Education Act (IDEA, Public Law 94-142) states that every child is entitled to an appropriate education and directs school districts to provide special

If they receive appropriate treatment, most children with kidney disease can attend school and graduate from high school. Many go on to college or vocational school.

services to ensure that children with disabilities are able to participate in regular classrooms to the fullest possible extent. Your child may need tutoring or vocational rehabilitation. Work with school counselors to find the best arrangement for letting your child work at a comfortable pace while also spending time with other children.



National Institute of Diabetes and Digestive and Kidney Diseases  
NATIONAL INSTITUTES OF HEALTH



U.S. Department of Health  
and Human Services

## Dealing With Low Self-Esteem

The physical effects of kidney disease can make children feel depressed and powerless. Learning and growth problems may contribute to low self-esteem. Children with functioning transplants seem to have fewer problems because they are less dependent on health professionals. Children who have as much control and responsibility as possible over their own care can feel empowered. Older children can take the lead in performing their peritoneal dialysis exchanges, preparing home hemodialysis equipment, and learning about their medication doses and purpose.

## Following Medical Instructions

Health professionals use the terms “noncompliance” or “nonadherence” to describe a patient’s failure or refusal to take prescribed medicines or follow a doctor’s directions. Teenagers with transplanted organs may be noncompliant because the immunosuppressive drugs they must take change their appearance in unflattering ways. A child psychologist may be able to suggest techniques that reinforce desired behaviors. But communicating clearly about the reasons for treatment and the importance of following the regimen is an important part of helping all patients, including children. Children who understand that their decisions can affect their health are more likely to take responsibility for their actions.

## Engaging in Sports or Physical Activity

In some cases, a doctor may recommend that a child restrict physical activity and get plenty of bed rest. In general, however, exercise has physical and psychological benefits. Parents or guardians may feel protective of a sick child, but they should not try to limit their child’s activity unless instructed by a doctor. Some children may even need to be encouraged to get outside and play to control blood glucose

and improve their blood pressure and the condition of the heart.

People with transplanted organs have demonstrated the ability to compete in sports. Not everyone can be an exceptional athlete, but 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.

## Making Friends

Children with kidney disease may have trouble fitting in with children of their own age because of their small stature, their delayed cognitive development, or the physical effects of immunosuppressive drugs. Some child psychologists specialize in helping to integrate children with disabilities and medical problems into mainstream activities. Participating in regular classroom and extracurricular activities can help your child develop social skills. Many areas have summer camps for children with special needs. Your clinic’s social worker may be able to help you find appropriate activities.

## Preparing to Enter the Work Force

Young adults who have been treated for kidney failure during childhood must overcome a number of barriers to prepare for a career and find a job. The effects of kidney disease can make learning and academic achievement difficult. Completing the training required for employment takes extra effort, and some people with kidney disease report that their small stature creates problems in fitting into adult environments. Employers may have trouble understanding kidney problems and may be reluctant to hire someone whose medical problems could raise their group insurance rates. Those with functioning transplants generally fare best in finding satisfying jobs.

## People Who Can Help

Many skilled professionals are available to ensure that your child gets the best possible care. In addition to the medical staff at your clinic, you should meet with people whose job is to help you find the resources you need so you can fulfill your other obligations at work and home.

### Social Worker

Every dialysis clinic and transplant center has a social worker who can help you locate financial assistance, identify social services like transportation or family counseling, and help with applications for Medicare. The social worker can tell you about support groups in your community and ways to reduce the stress of caring for a child with a chronic illness.

### Psychologist, Psychiatrist, or Counselor

Kidney disease can disrupt a child's life and create emotional turmoil. A psychologist or counselor can help your child find ways to express emotions constructively. Adults and siblings may also find that counseling helps them with the conflicts and stresses they face. For example, medical bills can strain family finances. A parent or guardian may need to give up work to care for the child full-time. Siblings may feel resentment over the huge amount of attention given to their sibling and guilt over thinking bad thoughts about the sick child. Couples sometimes report increased tension in their marriage when a child is sick. A counselor can help families deal with conflicts, and social workers or financial counselors can help families meet the financial obligations that chronic illness creates.

## Resources

### Websites

Several agencies and organizations maintain informative websites for people with kidney disease. The following sites are designed specifically for children and their parents or guardians:

#### **MEDLINEplus: Kidney Diseases (General)**

[www.nlm.nih.gov/medlineplus/  
kidneydiseasesgeneral.html](http://www.nlm.nih.gov/medlineplus/kidneydiseasesgeneral.html)

The National Library of Medicine maintains MEDLINEplus, a resource providing health information for consumers. The page on kidney diseases contains links to news articles and fact sheets about kidney diseases under many headings, including "Children."

#### **The Nemours Foundation's KidsHealth.org**

[http://kidshealth.org/parent/medical/kidney/  
chronic\\_kidney\\_disease.html](http://kidshealth.org/parent/medical/kidney/chronic_kidney_disease.html)  
[http://kidshealth.org/kid/feel\\_better/things/  
dialysis.html](http://kidshealth.org/kid/feel_better/things/dialysis.html)

The Nemours Foundation supports children's hospitals in Delaware and Florida. The KidsHealth website includes articles on many health topics written for parents, teenagers, and young children. The pages listed above contain "When Your Child Has a Chronic Kidney Disease" and "What's the Deal With Dialysis?"—an article written for children. You can view "Related Articles" and several more KidsHealth pages devoted to kidney diseases and their treatments.

#### **National Kidney Foundation: Children With Chronic Kidney Diseases: Tips for Parents**

[www.kidney.org/general/atoz/content/  
tipsparents.html](http://www.kidney.org/general/atoz/content/tipsparents.html)

The National Kidney Foundation has developed many programs to help support and educate patients and their families. This page contains "Children With Chronic Kidney Disease: Tips for Parents," which is also available in brochure form (see Additional Reading).

### **Nephkids Cyber-Support Group for Parents of Children With Kidney Disease**

<http://cnserver0.nkf.med.ualberta.ca/nephkids>

Nephkids is a listserv, an interactive email group for parents of children with various chronic kidney diseases.

### **Organizations**

Several groups offer information and services to patients with kidney disease. You may wish to contact one of the following:

#### **American Association of Kidney Patients**

3505 East Frontage Road

Suite 315

Tampa, FL 33607

Phone: 1-800-749-2257 or 813-636-8100

Email: [info@aakp.org](mailto:info@aakp.org)

Internet: [www.aakp.org](http://www.aakp.org)

#### **American Kidney Fund**

6110 Executive Boulevard

Suite 1010

Rockville, MD 20852

Phone: 1-800-638-8299 or 301-881-3052

Email: [helpline@akfinc.org](mailto:helpline@akfinc.org)

Internet: [www.kidneyfund.org](http://www.kidneyfund.org)

#### **American Society of Pediatric Nephrology**

James Whitcomb Riley Hospital for Children  
Wells Research Center

702 Barnhill Drive, 2600A

Indianapolis, IN 46202

Phone: 317-278-0854

Internet: [www.aspneph.com](http://www.aspneph.com)

#### **Life Options Rehabilitation Program**

c/o Education Institute Inc.

414 D'Onofrio Drive

Suite 200

Madison, WI 53711-1074

Phone: 1-800-468-7777 or 608-232-2333

Email: [lifeoptions@MEIresearch.org](mailto:lifeoptions@MEIresearch.org)

Internet: [www.lifeoptions.org](http://www.lifeoptions.org)

[www.kidneyschool.org](http://www.kidneyschool.org)

### **National Kidney Foundation**

30 East 33rd Street

New York, NY 10016

Phone: 1-800-622-9010 or 212-889-2210

Email: [info@kidney.org](mailto:info@kidney.org)

Internet: [www.kidney.org](http://www.kidney.org)

### **United Network for Organ Sharing**

P.O. Box 2484

Richmond, VA 23218

Phone: 1-888-894-6361

Internet: [www.unos.org](http://www.unos.org)

### **Additional Reading**

If you would like to learn more about kidney failure and its treatment, you may be interested in reading these publications:

#### *Adventure at Riverside Park: A Story About Pediatric Dialysis*

This story describes a young girl's experiences and emotions as a peritoneal dialysis patient. The book introduces the members of the health care team and explains the role each plays in dialysis treatment.

National Kidney Foundation of Indiana, Inc.

850 North Meridian Street

Suite 203

Indianapolis, IN 46204-1108

Phone: 1-800-382-9971

#### *Children With Chronic Kidney Disease: Tips for Parents*

#### *Nutrition and Peritoneal Dialysis*

National Kidney Foundation

30 East 33rd Street

New York, NY 10016

Phone: 1-800-622-9010

*Kidney Disease in Children*

*Kidneys for Kids*

"The Kid," a booklet written for children with kidney disease

*Diet Guide for the CAPD Patient*

American Kidney Fund

6110 Executive Boulevard

Suite 1010

Rockville, MD 20852

Phone: 1-800-638-8299

*Medicare Coverage of Kidney Dialysis and Kidney Transplant Services*

Publication Number CMS-10128

U.S. Department of Health and Human Services

Centers for Medicare & Medicaid Services

7500 Security Boulevard

Baltimore, MD 21244-1850

Phone: 1-800-MEDICARE

TDD: 1-877-486-2048

Internet: [www.medicare.gov](http://www.medicare.gov)

*Financing Transplantation: What Every Patient Needs to Know*, 2nd edition, 1996

United Network for Organ Sharing

P.O. Box 2484

Richmond, VA 23218

Phone: 1-888-894-6361 to order

single copies

(804) 782-4841 to order bulk copies

Internet: [www.unos.org](http://www.unos.org)

Newsletters and Magazines

*Family Focus Newsletter* (published quarterly)

National Kidney Foundation

30 East 33rd Street

New York, NY 10016

Phone: 1-800-622-9010

*For Patients Only Magazine* (published six times a year)

20335 Ventura Boulevard

Suite 400

Woodland Hills, CA 91364

Phone: 818-704-5555

*Renalife Magazine* (published quarterly)

American Association of Kidney Patients

3505 East Frontage Road

Suite 315

Tampa, FL 33607

Phone: 1-800-749-2257 or 813-636-8100



# National Kidney and Urologic Diseases Information Clearinghouse

3 Information Way  
Bethesda, MD 20892-3580  
Phone: 1-800-891-5390  
Fax: 703-738-4929  
Email: [nkudic@info.niddk.nih.gov](mailto:nkudic@info.niddk.nih.gov)  
Internet: [www.kidney.niddk.nih.gov](http://www.kidney.niddk.nih.gov)

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services. Established in 1987, the clearinghouse provides information about diseases of the kidneys and urologic system to people with kidney and urologic disorders and to their families, health care professionals, and the public. NKUDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about kidney and urologic diseases.

Publications produced by the clearinghouse are carefully reviewed by both NIDDK scientists and outside experts. NKUDIC would like to thank Barbara Fivush, M.D., and Kathy Jabs, M.D., of the American Society of Pediatric Nephrology (ASPN), for coordinating the review of this fact sheet by the ASPN's Clinical Affairs Committee: Tej Mattoo, M.D., William Primack, M.D., Joseph Flynn, M.D., Ira Davis, M.D., Ann Guillott, M.D., Steve Alexander, M.D., Deborah Kees-Folts, M.D., Alicia Neu, M.D., Steve Wassner, M.D., John Brandt, M.D., Manju Chandra, M.D., Frederick Kaskel, M.D., Ph.D., President, ASPN, and Sharon Andreoli, M.D., Secretary-Treasurer, ASPN, also provided comments and coordination.

This publication is not copyrighted. The clearinghouse encourages users of this fact sheet to duplicate and distribute as many copies as desired.

This fact sheet is also available at [www.kidney.niddk.nih.gov](http://www.kidney.niddk.nih.gov).



U.S. DEPARTMENT OF HEALTH  
AND HUMAN SERVICES  
National Institutes of Health

NIH Publication No. 04-5165  
October 2003

