

Kids With Kidney Disease Can Realize Their Dreams and Live Long, Normal, Productive Lives

By Gordon Lore

It is important upfront to realize and believe that, like many adults, children with kidney failure requiring dialysis and/or a renal transplant can live long, normal, productive lives. And equally important: kidney kids can realize their dreams! While there will be barriers to jump and setbacks to overcome, there will also be the ultimate triumph of living happy lives. Your parents, friends, and renal healthcare team will be especially helpful to you.

The most important person on your healthcare team is you, the patient. Never missing a treatment and strictly adhering to your medication and dietary regimens are very important for you to remain as healthy and active as possible.

The Kidney's Major Functions

Kidneys have two major functions:

- (1) To clear the body of extra fluid; and
- (2) Rid the body of waste products.

This and other information about the importance of your kidneys are discussed in one of the two articles now posted in this section of *KidneyTimes*.

Pediatric vs. Adult Kidney Failure

Renal failure in children is quite different than the same disease in

adults. It's a complicated chronic condition that affects many aspects of a child's life.

Kidney failure is much less common in children than in adults. New cases appear at a rate of around 11 children per million Americans compared to nearly 200 adult cases per million for the overall US population.

Most Common Causes

For children under the age of 12, the most common causes of kidney failure are structural problems with the kidney, bladder, or elsewhere along the urinary tract. Many children are born with these problems.

In children older than 12, glomerulonephritis (GLN, or inflammation of the kidneys) is the most frequent cause of kidney failure compared to diabetes for adults. GLN can also occur in children under the age of 12. Not all cases of this condition lead to renal failure, but some do. One kind of GLN which can lead to kidney failure is focal segmental glomerulosclerosis, or scarring of the kidneys.

While diabetes and hypertension are the most frequent causes of kidney failure in adults, these conditions rarely cause renal failure in children.

The Renal Healthcare Team

Members of a child's healthcare team include:

- A pediatric nephrologist (a doctor whose specialty is kidney disease in children);
- Nurses with expertise in pediatric dialysis and transplantation;
- A renal dietitian;
- Social worker;

- Urologist;
- A pediatric surgeon;
- Pharmacist;
- Psychiatrist and/or psychologist; and
- Even physical, occupational, and speech therapists may be needed.

Growth Failure

The main goal of treatment for pediatric kidney patients is to provide the most normal lifestyle possible for a child to grow and mature. A common problem in children with chronic kidney disease (CKD), however, has to do with a failure to grow.

The good news? In recent years, this failure to grow has been offset in many children with new advances in human growth hormone therapy, nutritional supplements, and human recombinant erythropoietin (EPO).

Get That New Kidney!

Getting a transplant as soon as possible is considered the best and most effective treatment for children with kidney failure. Transplanted kidneys can come from a cadaveric donor (someone who has donated his/her kidney immediately following death), or from a living or living-related donor since just about everyone has a "spare" kidney, much like a car has a spare tire.

Nearly four out of every 10 children, however, still require dialysis treatments while they are waiting for a new kidney, have a transplant that has failed, or are not considered appropriate candidates for a transplant.

Hemodialysis

Hemodialysis (HD) is the most common form of dialysis treatment for both children and adults. For kids, it is performed in an in-center unit for children up to age 19. Once the child reaches that transition age, he/she is transferred to an adult unit (see article elsewhere in this section).

During HD, the child is attached to a machine that removes blood from the body and cleans it of toxins and waste material while removing extra fluid. Then all the blood is returned to the body.

Peritoneal Dialysis

Some children may qualify for peritoneal dialysis (PD), a modality of treatment that is performed by the patient and his/her family at home.

There are two kinds of PD:

- (1) The most common is continuous ambulatory PD (CAPD). Children and their family members perform what are called "exchanges" several times a day. This treatment requires the placement of a special solution, or dialysate, into the patient's peritoneal cavity (PC) in the abdomen. The solution sits or "dwells" in the PC for a specific amount of time. Then it is drained out and a new solution replaced. This procedure takes place 3-4 times daily.
- (2) The second treatment is continuous cycling PD (CCPD) in which the patient dialyzes at night while he/she sleeps.

Only your nephrologist and renal healthcare team can determine which is the best type of PD for you as a pediatric kidney patient.

Is a Transplant the Best Treatment?

Most experts believe that transplantation is the best treatment of choice for nearly all children with end-stage renal disease (ESRD). This allows the child an opportunity for better growth and more normal participation

in school and other activities. Perhaps most importantly, the child is free of dialysis treatments as long as the new kidney is successfully functioning.

Like the adult transplant patient, however, the pediatric patient will also have to take certain medications known as immunosuppressive drugs to prevent the new kidney from being rejected. This is necessary because the body's defense system will recognize the new kidney as "a foreign intruder" and will attack it. These anti-rejection drugs act to prevent such an attack and will have to be taken every day for the rest of the life of the kidney. Fortunately, kidney transplants today last much longer than they used to, and more and more patients, even children, can live the rest of their lives with only one transplant.

Coping With Kidney Failure

Helping children and their families cope with renal failure is an extremely important aspect of the disease. Kids have special medical, social, and emotional needs, and it is important to help them feel as much like their peers as possible.

Parents should be encouraged to have the kidney kid continue attending school as much as possible in order for the child not to fall behind his/her peers. Part of the parent's job is to keep the school informed about their child's treatments, office visits, and hospitalizations, stressing the necessity of a renal diet.

After the ESRD Diagnosis...

After the diagnosis of ESRD is made or even anticipated, the child and his/her parents can meet the renal healthcare team. They can also be shown the dialysis center their child will attend and examine the equipment and procedure.

Both the patient and his/her family should be encouraged to ask whatever questions they may have about the treatment and its efficacy and safety.

"A Family Affair"

As it is with adults, pediatric patients and their families will experience greater than normal stress while dealing with kidney failure. Stress and worry place an added burden on any family, but remember that any chronic illness is "a family affair." Your unit's social worker can help you when you need emotional or financial support.

Continued love, support, and understanding of the family are perhaps the most important things family and friends can do to help a child or teenager deal with kidney failure. It is also important to know that many children who are diagnosed with kidney failure at a very young age can also lead normal, long, and productive lives in a positive cocoon of the three H's (Health, Happiness, and Hope).

Current and Future Postings

We are launching this Family and Kidney Kids Corner section with excellent articles on what kids should know about their kidneys and tips on transferring from a pediatric dialysis facility to an adult unit. There are also two fun trivia fill-in-the-blanks and multiple choice quizzes and a page of helpful websites kidney kids and family members can log onto.

In future postings, we hope to have a lot of useful information that kids and their parents can use. This may include helpful information and tips on:

- Further information about what your kidneys are and what they do.
- Dialysis treatment modalities (HD, PD, and transplantation).
- A guide for parents.

- A guide for teachers.
- The renal healthcare team.
- Emotional issues.
- Family issues.
- Eating concerns.
- Self-esteem.
- Growth failure.
- Special teen issues.
- Behavioral changes.
- Coping with depression and stress.
- Dealing with feelings.
- Handling and adhering to your medication schedule.
- Exercise.
- Travel.
- Back to school.
- Peer pressure.
- Patient profiles.
- Kidney Kids camps.
- Kidney Kids Calendar.
- Tips on helping you to look and feel better about yourself and your disease.