Home > Pediatric Kidney Disease > Introduction to Pediatric Kidney Disease

### **Introduction to Pediatric Kidney Disease**

This following class will share information about pediatric kidney disease. To navigate the class, simply use the left and right arrows at the bottom of the page or your browser's arrows at the top.

### Introduction

Chronic Kidney Disease (CKD) is the slow loss of kidney function over time and the final stages are called end-stage renal disease (ESRD). Once kidney function reaches ESRD, patient?s options for treatment become limited to dialysis and transplants.

• For more information on CKD, please visit [1]

When asked to picture a typical end-stage renal disease (ESRD) patient, most imagine someone who is of advanced age, but of course this is only a subset of the patient population. Currently, 1 in 40,000 Americans under the age of 19 are suffering with ESRD and this number is likely low given known underreporting issues. (1)

Pediatric kidney disease is a term used to describe any type of kidney disease that develops in children under the age of 19. (2)

Kidneys in children as well as adults are important because they remove the extra fluids and waste from the body and help regulate blood pressure, ensure chemical balance and maintain the health of the bones.

The rates of CKD are substantially lower in children than adults, but the incidence of CKD is increasing steadily with poor and ethnic minority children disproportionally affected. (3)

African Americans in their late teens are three times more likely than Caucasians in the same age group to develop kidney failure. Diseases that damage the tiny blood vessels in the kidney are also more common minority children. Moreover, boys are nearly twice as likely as girls to develop kidney failure from birth defects, polycystic kidney disease, or other hereditary diseases.

These issues could be related to genetic susceptibility, but other factors may include socioeconomic differences and limited access to medical care.

Pediatric ESRD patients create unique challenges for healthcare providers that go beyond treating the disease itself.

- Higher rates of catheter use in children leading to higher infection rates (4)
- Growth related issues due to both the disease and treatment options
- Increased risk for cardiovascular issues and hypertension
- Damage to the development of other organs such as the liver and lungs
- Noncompliance with treatments (LINK TO LATER)
- Financial challenges for families
- Psychosocial issues (4)

### **Positive News**

According to Barbara Fivus, M.D., director of pediatric nephrology at the Johns Hopkins Children?s Center. ?Kidney disease occurs more often than we think, but it is also more treatable than we used to think, especially when caught early.? ?Children and adolescents should be monitored carefully because kidney disease that seems to suddenly strike young adults often has its roots in childhood.? (5)

Increasing awareness among the general population is important to not only reduce the complications of those suffering with pediatric CKD, but also could help reduce the future prevalence of the disease.

### References

- 1. Ahmed, Rachel. (May 25, 2010). *Pediatric Kidney Disease Symptoms*. Retrievedfrom <u>http://www.livestrong.com/article/131281-pediatric-kidney-disease-symptoms/</u> [2].
- U S Renal Data System. (2011) USRDS 2011 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, Chapter Eight Pediatric End-Stage Renal Disease. Retrieved from http://www.usrds.org/2011/pdf/vs\_ch08\_11.pdf [3].
- 3. National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC). (2010), *Overview of Kidney Diseases in Children.* Retrieved from http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview [4].
- 4. U S Renal Data System. (2005) USRDS 2005 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States Chapter Eight Pediatric End-Stage Renal Disease. Retrieved from http://www.usrds.org/2005/pdf/08\_pediatric\_esrd\_05.pdf [5].
- 5. *Moving Toward a Better Understanding of Childhood Kidney Disease*. (2010). Retrieved from <u>http://www.hopkinschildrens.org/understanding-childhood-kidney-disease.aspx</u> [6].

# What are the Symptoms Associated with Pediatric Kidney Disease?

Kidney disease often goes undetected in the general population, but children and

adolescents are at an even greater risk due to the nature of the causes of the diseases and the ambiguity of the symptoms.

- In adults, 90% of cases are related to glomerular based renal disease caused by diabetes, hypertension and glomerulonephritis, which cues physicians to suspect kidney disease.
- In children, 70% of CKD is associated with tubulointerstitial disease and lack the obvious symptoms such as hematuria (red blood cells in the urine), hypertension (high blood pressure) or edema (swelling). (1)

Adding to this difficulty, children might not be aware of some of the changes that are impacting their body and will not always let their parents know of potential issues.

Common symptoms for children are:

- Swelling (even mild) of the hands and feet and/or puffiness around the eyes caused by excess fluid build-up, to the point where the child?s ability to move around normally is compromised
- After initial swelling, socks or a belt can leave an indentation in the skin that will persist
- Lack of or decrease in appetite.
- In children with ESRD it is especially important to keep their appetite up because transplant eligibility is based partially on growth.
- · Decreased or increased frequency of urination. Children who can normally use the toilet without assistance may suddenly begin to wet the bed at night
- · Long-lasting changes in the color of the urine such as unusually dark or red, which can indicate blood, and changes in appearance of urine such as extra foam that can indicate protein
- Headaches resulting from high blood pressure (2)
- Flu-like Symptoms such as nausea, vomiting, weakness, fatigue, loss of appetite
- Stunted or poor growth as compared to similar age group peers
- Difficulty concentrating and poor school performance

Another potential indicator of pediatric kidney disease is family history of kidney disease. Genetic related disease is much more common in children than in adults. If there is family history, it is a good idea to get a check-up.

In parents that are pregnant with a child with polycystic kidney disease a common symptom is decreased amniotic fluid.

Looking at the list of common symptoms it is easy to see how CKD can go undiagnosed. As a parent or caregiver, it is important to have conversations with your children to understand the severity and duration of the symptoms and follow up with your primary care physician.

### References

1. Bunchman, Timothy E. (2008) Pediatric Chronic Kidney Disease: Lack of Overt Symptoms Makes Diagnosis Challenging. Nephrology Times. Volume 1(4). Retrieved from http://journals.lww.com/nephrologytimes/Fulltext/2008/04000/Pediatric\_Chronic\_Kidney\_Disea  Kids Health. Kidney Diseases in Childhood. (2009). Retrieved from <u>http://kidshealth.org/parent/medical/kidney/kidney\_diseases\_childhood.html#a\_Symptoms\_of\_</u> [8].

## Diagnosis

### Non-invasive Methods

These are methods, like a basic physical examination and medical history, where the doctor will look for signs such as swelling that will prompt additional tests. The doctor will also review family medical history to determine if more tests are necessary.

- **Urinalysis** is a quick urine strip test that may or may not include microscopic analysis. It can quickly detect abnormalities such as traces of blood that may indicate inflammation or irritation in the urinary tract. Urinalysis can also detect an excess of white blood cells, which is most commonly associated with infections.
- **Microalbuminuria** ? is an additional more in depth urinalysis that is used to detect albumin in the urine. This test is often done when protein comes out negative in a basic urine test, but the patient has risk factors that could indicate kidney disease.
- **Creatinine Clearance** ? is another more in depth 24 hour urine collection test. It is used to give a total picture of kidney function instead of just a point in time like the urine stick test.

Two other important diagnostic indicators used by doctors are blood pressure and growth measurements. Along with the heart, the kidneys are crucial to regulating blood pressure. Since high blood pressure is rare in children it is a warning sign that the kidneys need further evaluation. Additionally, accurate growth measurements can provide a clue to diagnosing some kidney diseases, because children with chronic kidney disease often grow poorly.

### **Imaging studies**

Are usually suggested by a nephrologist, a doctor who specializes in the diagnosis and treatment of kidney diseases.

- **Standard X-rays** are used to capture an image of the body that can be used to determine the presence of kidney stones and can sometimes be used to measure physical characteristics of the kidney.
- Angiography or an angiogram is an imaging technique that uses x-rays and contrast dye to view your body?s blood vessels. This test is commonly used to assess blockages or narrowing of the renal artery.
- Intravenous Urography (IVU) is another imaging technique that uses contrast dyes to measure the size and shape of the pelvis and ureters.
- **Ultrasounds** are the most common imaging study and are used to show the details of the kidney, including size, appearance, anomalies, blockages of urine, and tumors. Ultrasound is painless and importantly does not require the use of radiation.
- Computerized tomography (CT) Scans uses a computer to create three-

dimensional imagery of a series of x-rays. They are useful for revealing the anatomy of the kidneys or bladder and, in some cases, are better than ultrasounds for finding kidney stones. CT scans however, do have the risk of radiation exposure and sometimes have additional risks due to use of intravenous contrast dye.

• Magnetic resonance imagery (MRI) - uses a magnetic field and a computer system to create a detailed picture of the kidney. The result is similar to the functions of the CT scan. Recently, the contrast dye gadolinium, used in MRIs, has been associated with nephrogenic systemic fibrosis (NSF), a potentially fatal skin disease in patients with decreased kidney function.<sup>1</sup>

#### Invasive

Imaging studies can still only tell so much. Additional blood tests are necessary for doctors to determine how well the kidneys are filtering waste products and balancing the bloodstream's chemical makeup.

- Serum creatinine creatinine is a waste product produced by the muscles that is filtered through the kidneys. Blood creatinine levels can demonstrate how well the kidneys are working overall. Creatinine levels though can be tricky due to differences in measurement techniques and muscle mass, especially when applied to children.
- Blood Urea Nitrogen (BUN) ? urea is a product of protein from food that is broken down in the body. It is a solid indication of kidney function because the level of urea rises as kidney function declines.
- **Glomerular filtration rate (GFR)** is the current gold standard test of how much the kidneys are working. Estimated GFR is calculated based off of factors such as blood creatinine levels, age, sex and other indicators to provide an idea of how well the kidneys are functioning.<sup>2</sup>
- Voiding cystourethrogram (VCUG) is commonly used to evaluate the bladder and Ureters. This procedure involves putting a dye into the bladder to see whether there is and obstruction or reflux of urine from the bladder back up to the kidneys when a child urinates.

In addition, other blood tests such as a **comprehensive metabolic panel (CMP)** are used to determine levels of sodium, potassium, calcium and phosphate to determine the extent of kidney failure. Physicians may also want to perform a **complete blood count (CBC)** that includes the levels of white and red blood cells, hemoglobin, platelets that can help determine issues such as infections and anemia.

The physician may also order a kidney biopsy to evaluate kidney function. A biopsy is a procedure in which a small piece of the kidney tissue is removed with a needle. The procedure is performed while a child is under anesthesia, it is a simple procedure that can help make an accurate diagnosis of the kidney failure in about 9 out of 10 cases.<sup>3</sup> It's especially helpful in the diagnosis of nephritis and nephrosis.

### References

- 1. Sagireddy, Purushottama, MD. Use of Radiological Tools for Evaluating Kidney Disease. Retrieved from <u>http://www.davita.com/kidney-disease/overview/symptoms-</u> and-diagnosis/use-of-radiological-tools-for-evaluating-kidney-disease/e/4725 [9].
- 2. National Kidney Foundation. *About Chronic Kidney Disease*. Retrieved from http://www.kidney.org/kidneydisease/ckd/knowgfr.cfm

[10].

3. Bacchetta, Justine, Cochat, Pierre, Rognant, Nicholas. (2010). Which Creatinine and Cystatin C Equations Can Be Reliably Used in Children. *Clinical Journal of the American Society of Nephology.* Volume 6:3. Retrieved from <a href="http://cjasn.asnjournals.org/content/6/3/552.abstract">http://cjasn.asnjournals.org/content/6/3/552.abstract</a> [11].

# Causes

Kidney failure can be caused by many underlying issues and generally falls into two categories of disease, classified as acute or chronic. Acute diseases generally develop quickly, lasts for a limited amount of time and are more immediately severe than chronic conditions (think food poisoning). However, acute disease can also develop or cause lingering problems. Chronic diseases generally develop and worsen over time and do not go away.

In adults the most common causes of kidney failure are diabetes and hypertension. In children congenital defects causing urinary tract blockages (posterior urethral valves) or small or non-functioning kidneys (hypoplastic and dysplastic) or another disorder that causes scarring of the glomeruli that leads to nephrotic syndrome (Focal Segmental Glomerulosclerosis), are the most common causes. (1)

Until age 4, birth defects and hereditary diseases are by far the leading causes of kidney failure. Between ages 5 and 14, hereditary diseases continue to be the most common causes, but glomerular disease incidence rises. As children age past 15, glomerular diseases are the leading cause, and hereditary diseases become rarer.

### **Acute Diseases**

Acute kidney disease can come from poisoning, but often comes from an injury. Injuries that result in blood loss may temporarily reduce kidney function; however once blood loss is limited, the kidneys usually recover.

- Hemolytic uremic syndrome (HUS) is rare disease that affects children mostly under 10 years of age and can result in kidney failure. HUS is caused by eating foods contaminated by *Escherichia coli (E coli)* bacteria, which leads to an infection in the digestive system. Poisons produced by the bacteria can damage the kidneys, causing acute kidney failure. Children with HUS may need blood transfusion or dialysis for a short time. Most however, return to normal after a few weeks, and only a small percentage of children (mostly those who have severe acute kidney disease) will develop chronic kidney disease.
- Nephrotic Syndrome ? is a set of symptoms that tends to affect children ages 1½ and 5 years and is more commonly found in boys. A child with this syndrome will urinate less often, causing fluid to accumulate and produce swelling around the eyes, legs, and belly. The small amount of urine the body makes contains high levels of protein. Healthy kidneys keep protein in the blood, but damaged kidneys let it leak from the blood into the urine. Nephrotic syndrome is usually treated with prednisone to stop protein leakage, and sometimes a diuretic is used to help the child urinate and reduce the swelling. Usually, the child can take smaller and smaller doses of

prednisone and eventually return to normal with no lasting kidney damage. This temporary condition is called minimal change disease. Relapses are common but usually respond to additional prednisone treatment.

#### **Chronic Kidney Diseases**

Unfortunately, the conditions that lead to chronic kidney failure in children cannot be easily fixed. Often, the condition will develop silently and goes unnoticed until the kidneys have been permanently damaged. Treatment may slow down the progression of some diseases, but in many cases the child will eventually need dialysis or transplantation.

- **Birth defects** some babies are born without one or both kidneys or have abnormally formed or non-functioning kidneys. Kidney abnormalities can also be a part of a syndrome that affects many parts of the body.
  - Horseshoe kidney where the two kidneys are fused (connected) into one arched kidney that usually functions normally, but is more prone to develop problems later in life. An uncomplicated horseshoe kidney does not need medical or surgical treatment, but it does need to be checked regularly by doctors.
  - Fetal hydronephrosis ? is an enlargement of one or both of the kidneys is caused by either an obstruction in the developing urinary tract or a condition called vesicoureteral reflux (VUR) in which urine abnormally flows backward (or refluxes) from the bladder into the ureters. Fetal hydronephrosis is usually diagnosed before the child is born and treatment varies widely. In some cases the condition only requires ongoing monitoring; in others, surgery is the only way to clear the obstruction from the urinary tract.
- **Blocked urine flow and reflux -** if blockage develops between the kidneys and the opening where urine leaves the body, the urine can back up and permanently damage the kidney.
  - Posterior urethral valve obstruction this narrowing or obstruction of the urethra affects only boys. It can be diagnosed before the baby is born or just afterwards and treated with surgery.
  - **Congenital problems with the urinary tract ?** as a child develops in the womb, a part of the urinary tract can grow to an abnormal size or in an abnormal shape or position.
  - **Duplication of the ureters** ? is an example of a congenital defect, where a kidney has two ureters instead of one. This can lead to urinary tract infections over time and can be treated with medication or occasionally with surgery.
- **Polycystic Kidney Disease (PKD)** is a condition in which many fluid-filled cysts develop in both kidneys. The cysts develop, multiply and can lead to kidney failure. Most forms of PKD are inherited, and diagnosis can made before or after the child is born. One of the primary symptoms in expecting mothers is a lack of amniotic fluid. In some cases, there are no symptoms and in others, PKD can lead to urinary tract infections, kidney stones, and high blood pressure. Treatment for PKD also varies widely. In some cases, PKD can be managed with dietary changes, but in others it requires a kidney transplant or dialysis.
- **Multicystic Kidney Disease (MKD)** is when large cysts develop in the kidney that hasn't developed properly, eventually causing it to stop functioning. The difference

between PKD and MKD is that PKD affects both kidneys, while MKD usually impacts only one. Fortunately, the unaffected kidney takes over and most people with MKD will have normal kidney function. MKD usually is diagnosed by prenatal ultrasound before a baby is born. Doctors manage it by monitoring blood pressure and screening for a urinary tract infection when needed. In extremely rare instances, surgical removal of the kidney may be necessary.

- **Renal tubular acidosis -** is a condition in which the kidneys do not properly regulate the amount of acid in the body. It can cause kidney stones and affect a child's growth, but usually can be treated with medications.
- **Glomerulonephritis** is an inflammation or infection of the glomeruli. It can affect the kidney's ability to properly filter out waste and can lead to swelling, blood in the urine, and a reduced amount of urine production. Some cases can be treated with medication, while others require dialysis or a kidney transplant. If the damage to the glomeruli is severe, kidney failure may develop.
- **Systemic diseases** diabetes and lupus are the two most common syndromes in children and can affect many parts of the body, including the kidneys. In lupus, the immune system becomes overactive and attacks the body's own tissues. Diabetes leads to high levels of blood glucose that damage the glomeruli. In children, diabetes is low on the list of causes because it usually takes many years of high blood glucose for the kidney disease of diabetes to develop. However, an increasing number of children have type 2 diabetes, and as a result, we may see more children with chronic kidney failure caused by diabetes in the future. (2)

### References

- 1. Warady, Bradeley M.D. End-Stage Renal Disease in Children: What Causes it? Retrieved from <u>http://www.aakp.org/aakp-library/ESRD-in-Children/</u> [12].
- 2. National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC). (2010), *Overview of Kidney Diseases in Children.* Retrieved from <u>http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview [4]</u>.

### **Treatment Options**

Children with kidney failure have a few options to choose from, depending on the severity of their disease. The primary goal is to have a successful transplant, however viable kidneys are not always available and some children are not strong candidates for transplants.

In some cases a nephrectomy is a solution that can make childhood disease easier to manage.

In most cases parents choose home dialysis options either home hemodialysis or peritoneal dialysis.

### Transplants

In adults, most transplanted kidneys come from donors who have just perished. However, about half of the kidney transplants in children come from a living donor, usually a parent

or other close family member.

Those who do not have a relative able to donate a live kidney need to enter the United Network for Organ Sharing (UNOS) managed Organ Procurement and Transplantation Waiting List. (1) Candidates' ages and length of time on the waiting list are factors in the donor point system. Children aged 18 and under get extra points compared with adults, because they are likely to receive the greatest benefit from a donated kidney. (2)

- Living Donor Kidney A kidney from a living donor often has advantages over a kidney from a recently deceased individual. (3)
  - <sup>?</sup>A kidney from a parent is guaranteed to match on at least three of six proteins, which means it is less likely to be rejected.
  - With a living donation, there is additional time to pre plan and schedule the operation.
  - Shortens the number on the waiting list.
  - Psychological benefits of knowing that the donation came from a caring family member.
  - $\circ\,$  Live kidneys are more likely to be in good condition, because they do not need to be transplanted.

**Pre-emptive renal transplantation** - Is a transplantation before complete renal failure has occurred.

- Recent research out of the University of Washington shows increased graft and patient survival among preemptive transplant patients and the authors suggest that education of both the patients and the physicians could make preemptive transplantation an option for more children.
- Another article published in Touch Nephrology, cites the benefit of reduced morbidities from not being subjected to dialysis and reduced transplant rejection.
- Of course, ethical issues do come about with this topic, especially how patients would be selected given the abundance of individuals on the waiting list. (4)

<sup>?</sup>For children with ESRD who are awaiting a transplant, not a strong candidate or choose not to have surgery, dialysis is the only option.

Dialysis is a treatment used to clean the blood and remove waste when the kidneys are no longer able to do so.

There are two major types of dialysis:

- **Hemodialysis** can be done in the clinic or at home. In hemodialysis a machine is used with a special filter called a dialyzer that acts as an artificial kidney to remove wastes products and toxins from the blood.
- **Peritoneal dialysis** uses the lining of the child?s abdomen as a filter to remove fluids and toxins from the blood. A special catheter is used to introduce clean fluid and remove contaminants.

### Partners in Care Treatment Team

Understanding the members of the healthcare team is vitally important to ensure the best possible care is given.

As a parent or guardian you are the most important member of the team. You are the eyes and ears of the medical staff and will help convey your child?s thoughts and feelings to the rest of the team. You will also have the task of providing moral support and reassurance as a parent. It is important to remember that you are not alone and resources such as support groups and counselors are available to help you through the daily challenges.

- **Pediatrician** ? is the child?s primary doctor, who will likely be the first to diagnose or suspect kidney issues. Depending on their expertise, they will refer to a specialist and likely to a nephrologist. The pediatrician will continue to be a valuable resource even after referral.
- **Nephrologist** ? is a doctor that specializes in the care of kidneys and understands potential disorders. If possible, children should see a specialist that works primarily in pediatrics. The nephrologist is the one who will help manage any issues and provide referral to a transplant center or dialysis clinic.
- **Dialysis Nurse** ? if dialysis is needed, a nurse trained in dialysis will be the hands on expert to either perform dialysis in the clinic or teach the parent or guardian how to perform one of the home options. The nurse is an excellent resource to determine what type of dialysis might be right.
- **Transplant Coordinator** ? if a transplant is the chosen route, the transplant coordinator will be your main contact. They will schedule additional medical exams and ensure the paperwork is filed to put the child on the transplant list.
- **Social Worker** ? in either dialysis or transplantation, a social worker will work with you to handle the day to day situations that occur. They are an excellent resource and can help locate financial resources and recommend social services such as counseling.
- **Counselor** ? is a trained expert that will be a source of support for the entire family during the new and stressful times ahead. Their services can range from just being someone to listen to conflict and financial resolution.
- Genetic Counselor ? is an expert in genetics that can help figure out the exact root cause of the disease. They help to prempitively treat conditions and help with future family planning.
- **Dietician** ? is the expert who will help the child learn to live with the new restrictions of being a dialysis or transplant patient. Nutrition is often overlooked, but is extremely important to the health and well-being of the patient. Dieticians can help develop meal plans to deal with nutritional deficiencies and provide alternatives to already established family favorites. (3)

### References

- 1. United Network for Organ Sharing. Living Donation Information You Need to Know. From <u>http://www.unos.org/docs/Living\_Donation.pdf</u> [13].
- 2. Davis, CL. Preemptive Transplantation and the Transplant First Initiative. *Current Opinon in Nephrology and Hypertension.* Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/20827196</u> [14].
- 3. National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC). (2010). Treatment Methods for Kidney Failure in Children. Retrieved from http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview [4].
- 4. Segoloni, Giuseppe, Toqnarelli, Guiliana. Pre-emptive Kidney Transplantation. *European Nephrology*, 2010; 4 (1): 85-8. Retrieved from <u>http://www.touchnephrology.com/articles/pre-emptive-kidney-transplantation</u>

[15]

- 5. Hatch, David MD, Agrawal, Rekha, MD, Firlit, Casimir F. MD. Pediatric Kidney Transplantation Treatment and Management. Retrieved from http://emedicine.medscape.com/article/1012654-treatment#aw2aab6b4b4 [16].
- 6. Organ Procurement and Transplantation Network, About Transplantation. Retrieved from <u>http://optn.transplant.hrsa.gov/</u> [17].

### **Issues Specific to Children**

Children are not just little versions of adults. They endure their own physical and mental issues that deserve extra attention.

### Physical

### Immunizations

Early childhood is when several series of immunizations are scheduled, which can create additional issues in children with renal failure. Due to weakened immune systems, it is even more important that children with CKD receive all recommended vaccinations plus pneumonia and influenza.

- Children who are on immunosuppressive medication to prevent transplant rejection or treat an autoimmune disease should not receive live viruses though, those include the polio oral vaccine, the measles, mumps and rubella (MMR) vaccine or the varicella (chicken pox) vaccine.
- Of particular concern, is the rates of vaccination against influenza in the pediatric population remained alarmingly low in 2006?2009, with fewer than one in three patients age 14 or younger receiving a vaccination. (1)
- Also, children on immunosuppressive treatments may require additional or larger doses of immunosuppressive because they have a more active immune system than adults. Sustained usage of these drugs can lead to undesirable side effects such as weight gain, unusual hair growth and acne. These types of effects can lead to higher rates of noncompliance.

### Anemia

Another issue that disproportionately impacts children is anemia, which is a shortage of red blood cells or hemoglobin in the blood. This condition causes tiredness in most, but can cause damage to the organs and in rare cases death.

### Growth and Bone Development

Growth and bone development issues are another common set of problems in children with CKD. Since adults are nearly full grown at onset of CKD this is an issue that impacts children more.

Kidneys impact bone growth in two ways. First, they help regulate blood phosphorus levels that when too high, inhibit bone growth. Second, they help regulate calcium levels in the

blood that stimulates proper growth. Dietary changes that limit high phosphorus rich foods and medication to bind additional phosphate are necessary to reduce growth issues.

### **Health Outcomes**

In comparison with the general population, the long-term survival of children with advanced CKD remains low. Specifically, the lifespan of a pediatric patient on dialysis is shortened by nearly 50 years when compared with control individuals matched for age and ethnicity. Even after successful renal transplantation, their lifespan is reduced by 25 years, and although overall patient survival has improved, cardiovascular disease (CVD) accounts for the majority of deaths.

However, unlike adults, pediatric patients with CKD rarely demonstrate symptomatic atherosclerosis and diabetes mellitus. Children and adults also have different causes of death attributable to CVD. In adults, complications of congestive heart failure and myocardial infarction are the two leading causes of death. Cardiac deaths account for nearly 25 percent of deaths in children and young adults with end-stage renal disease,? notes Dr. Warady. (2)

By contrast, in children with advanced CKD, cardiac arrest is the major CVD-related cause of death.

Mortality rates are similar to what is seen in the adult population, with rates peaking in the second month after initiation of treatment, then slowly declining through the rest of the first year. In the early months of therapy, the youngest children are at the highest risk of both hospitalization and death.

The most striking findings related to pediatric ESRD patients continued to center on the extreme vulnerability of patients younger than ten, and issues of infection control, which could lower the rate of complications, need to be addressed.

### Emotional

Treating the emotional impact of renal failure is just as if not more important than treating the physical aspects. Being seen as different is never easy, and having to take medication that can give adverse side effects, no matter how life saving, is difficult.

The isolation people feel because of kidney failure is especially a problem in children and adolescents because of the importance of making friends and fitting in at this age. Finding the best treatment for a child takes on special significance to ensure that the child with kidney failure can become an active, productive, well-adjusted adult. (2)

Pediatric-only centers are becoming more wide spread, but emotional issues can be magnified when children are treated in adult settings. When young adults have complex health needs, the traditional pediatric and adult services approach is unlikely to provide the environment and support needed to allow the young person the best chance of achieving his or her aims and aspirations in life. (3)

These cultural barriers between pediatric and adult healthcare are an additional burden and pose substantial risks to teenagers or young people with chronic illness, requiring ongoing clinical management. The transitional years are a time of increasing independence, experimentation, and rebellious behavior that may manifest as nonadherence. In end-stage kidney disease, United States data demonstrate reduced 5-year transplant survival rate (57%) in teenagers compared with adults aged 40-49 (72%).

Transfer from holistic focused pediatric care clinics to large adult kidney care programs can lead to significant no adherence leading to high levels of premature transplant failure.

When children do reach the age where it is appropriate to go to an adult focused clinic there are still transition issues. Some children can handle this change easily, while others will struggle. Transition occurs over a period of time. It should be a process that addresses the medical, psycho-social, educational, and vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented healthcare systems

Children with advanced kidney disease on dialysis or who have undergone transplantation are often managed at regional centers, sometimes a long distance from their homes and local communities. But kidney disease is far more common in adults, and, therefore, there may be a large geographical separation between the children's and the adult's services, which adds to the complexity and logistic difficulties. Lack of transitional planning can generate anxiety in patients, parents/caregivers, and staff.

Better results are achieved when young people are given the opportunity to meet their future adult multiprofessional team in a range of settings and on a number of occasions before "moving" to the adult unit. Young people receive a great deal of support from peers and can also benefit from contacts with young adults who have already transferred to the adult unit In addition use of text messaging, e-mails, and social network sites can facilitate interaction between the young adult patient and the adult healthcare team as well as catalyzing valuable peer interaction. In another example, hosting follow-up clinics in a student college or even a local cafe can help customize the teenage patient to the young adult clinic.

### References

- U S Renal Data System. (2011) USRDS 2011 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, Chapter Eight Pediatric End-Stage Renal Disease Retrieved from <u>http://www.usrds.org/2011/pdf/vs\_ch08\_11.pdf</u> [3].
- 2. National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC). (2010), Growth Failure in Children with Kidney Diseas. Retrieved from http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview [4].
- 3. U S Renal Data System. (2010) USRDS 2010 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, Chapter Eight Pediatric End-Stage Renal Disease from <u>http://www.usrds.org/2010/pdf/V2\_08.pdf</u> [18].

### Resources

### The Nemours Foundation's Tips for Parents

• http://kidshealth.org/parent/medical/kidney/chronic\_kidney\_disease.html [19]

### The Nemours Foundation's KidsHealth.org

• http://kidshealth.org/kid/feel\_better/things/dialysis.html [20]

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

• https://www.kidney.org/atoz/content/childckdtips [21]

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

• cybernephrology.ualberta.ca/nephkids/ [22]

### **Childhood Kidney Support Network**

• https://ksn.org.au/how-we-help/childhood-ksn/ [23]

# **Choose Another Class**

Congratulations on finishing the class! Please choose another class from the list below to continue your journey.

© 2017 The Dialysis Patients Citizens (DPC) Education Center. All rights reserved. Unauthorized use prohibited. The information contained in this website is not a substitute for medical advice or treatment, and consultation with your doctor or healthcare professional is strongly recommended. The DPC Education Center is a section 501(c)(3) non-profit charity (37-1698796). Contributions are tax deductible to the fullest extent permitted by the law.

Source URL: http://www.dpcedcenter.org/classroom/introduction-pediatric-kidney-disease

### Links

[1] http://dpcedcenter.org/classroom/heart-matter/chronic-kidney-disease-and-cardiovascular-disease

- [2] http://www.livestrong.com/article/131281-pediatric-kidney-disease-symptoms/
- [3] http://www.usrds.org/2011/pdf/vs\_ch08\_11.pdf
- [4] http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview
- [5] http://www.usrds.org/2005/pdf/08\_pediatric\_esrd\_05.pdf
- [6] http://www.hopkinschildrens.org/understanding-childhood-kidney-disease.aspx
- [7]

http://journals.lww.com/nephrologytimes/Fulltext/2008/04000/Pediatric\_Chronic\_Kidney\_Disease\_\_Lack\_of\_Overt.12 [8]

http://kidshealth.org/parent/medical/kidney/kidney\_diseases\_childhood.html#a\_Symptoms\_of\_Kidney\_Problems [9] http://www.davita.com/kidney-disease/overview/symptoms-and-diagnosis/use-of-radiological-tools-for-

evaluating-kidney-disease/e/4725

[10] http://www.kidney.org/kidneydisease/ckd/knowgfr.cfm

[11] http://cjasn.asnjournals.org/content/6/3/552.abstract

[12] http://www.aakp.org/aakp-library/ESRD-in-Children/

[13] http://www.unos.org/docs/Living\_Donation.pdf

[14] http://www.ncbi.nlm.nih.gov/pubmed/20827196

[15] http://www.touchnephrology.com/articles/pre-emptive-kidney-transplantation

[16] http://emedicine.medscape.com/article/1012654-treatment#aw2aab6b4b4

[17] http://optn.transplant.hrsa.gov/

[18] http://www.usrds.org/2010/pdf/V2\_08.pdf

[19] http://kidshealth.org/parent/medical/kidney/chronic\_kidney\_disease.html

[20] http://kidshealth.org/kid/feel\_better/things/dialysis.html

[21] https://www.kidney.org/atoz/content/childckdtips

[22] http://cybernephrology.ualberta.ca/nephkids/

[23] https://ksn.org.au/how-we-help/childhood-ksn/