

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Care of a Child with Chronic Kidney Disease



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11 FAQs on CARE OF A CHILD WITH CHRONIC KIDNEY DISEASE

1. My child looks absolutely fine and has no problems or symptoms. Then why are you saying that his kidneys are not working well? He would be sick if that were true, is it not?
2. So, if symptoms develop late in chronic kidney disease, when should we suspect or worry about our child's kidney function?
3. My child is passing urine very well. Then how is it that both the kidneys are damaged?
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10. Is there any better treatment available besides lifelong dialysis?
11. Can I donate my kidney to my child? How long will the new kidney work in my child?

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Care of a Child with Chronic Kidney Disease

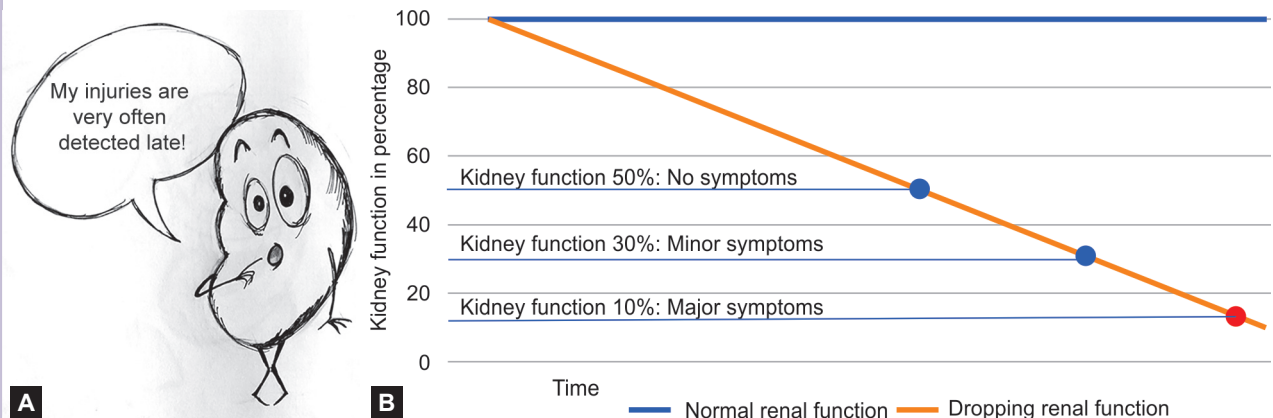
Q1

My child looks absolutely fine and has no problems or symptoms. Then why are you saying that his kidneys are not working well? He would be sick if that were true, is it not?

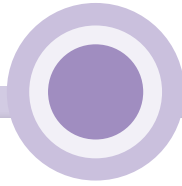
The diagnosis of kidney disease for the first time in a child who looks normal is taken with skepticism by the parents. Kidneys have two basic functions; eliminating waste products and preserving the good substances. A problem in eliminating waste products is termed as “kidney failure”.

When kidneys work at 100%, obviously a person/child does not have any symptoms related to the kidneys. However, when the kidney function starts reducing, the child will still continue to feel fine.

As shown in the graph (**Figs. 1A and B**), even when the kidney function has dropped to 50% of normal, there may be no symptoms or feelings of being unwell. When the kidney function drops to 30%,



Figs. 1A and B: Appearance of symptoms and % of kidney function.



there may be very minor symptoms such as lethargy and tiredness. When the kidney function drops to around 10–15%, catastrophic symptoms may occur such as persistent vomiting, nausea, breathlessness, convulsions, etc. At this stage, dialysis or transplantation is the only treatment possible.

It takes a long time for the kidney function to drop to very low levels and in this period, the child will feel completely fine. Interventions that may help to preserve kidney function have to be done very early to be effective. It is important to know that only tests will reveal kidney dysfunction in a fit looking child. So, any of the children shown in **Figure 2** could be patients of kidney failure if they have certain risk factors. What we are describing here is called chronic kidney disease or CKD (meaning kidney dysfunction that has been present for a long time, >3 months).

This is quite different from an acute insult that might also lead to poor kidney function—termed as “acute kidney injury”. In this case, the damage is temporary and can be reversed by treating the cause.



Fig. 2: Any of these children could have a risk of developing chronic kidney disease (CKD).

Q2

So, if symptoms develop late in chronic kidney disease, when should we suspect or worry about our child's kidney function?

This is an important question. As explained, symptoms may appear late in CKD. Hence, we need to be aware of the potential conditions where kidney function may get affected. Besides waste removal, kidneys also help in production of red blood cells, facilitating growth and maintaining blood pressure.

- Let us start at the very beginning. Decreased amniotic fluid (fluid around the baby on antenatal scans) is one of the earliest signs that could tell us that the kidney function of the baby may be affected. This is because the water around the baby is mostly urine expelled by the kidneys of the fetus. In such cases, kidney function tests and ultrasound have to be done after that baby is born and monitored later on too.
- Any abnormality seen on the antenatal ultrasound scans such as a single kidney, widening of the urinary tract, one smaller kidney or cysts in the kidneys needs to have careful monitoring of the kidney functions after birth and monitoring later.
- A child getting repeated urinary infections or any urinary symptoms such as urgency, dribbling, and poor stream needs evaluation.
- Growth of the child with regard to poor weight gain and being very short for age could point toward an underlying kidney disease.
- Persistent excretion of protein and blood in the urine and/or appearance of swelling over face in morning and subsequently spreading to all over the body for a long time indicates that the kidneys are at risk for injury.
- High blood pressure recording at routine doctor visits needs further work up.

Q3

My child is passing urine very well. Then how is it that both the kidneys are damaged?

One of the common misconceptions is that if the child is passing urine well, the kidneys are working well. Unfortunately in CKD, the amount of urine passed remains normal till the kidney function is <10%. This is because the quality of filtration in the kidney is affected while the quantity remains only mildly affected. So, having adequate urine does not mean that kidney function is normal.

Q4

Why does my child have chronic kidney disease? Is it genetic, related to food, or infection?

Most often, CKD is a consequence of developmental defects of the kidney that happens during fetal life. However, during childhood certain infections and diseases can also lead to CKD. In some instances, children could inherit kidney diseases from family members due to hereditary or genetic disorders. Foods or specific dietary habits do not directly lead to the occurrence of CKD.

It is important to note that we have two kidneys and both are affected in CKD. If one of the kidneys gets damaged, then the other normal kidney amazingly works harder, takes over the work of the damaged kidney and strives to maintain normal kidney function (**Fig. 3**).

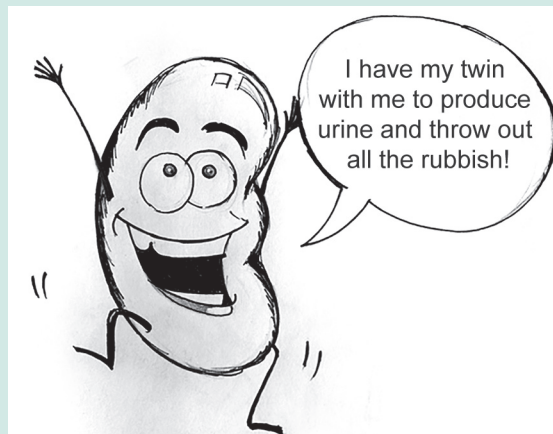


Fig. 3: One damaged kidney can receive support from the other healthy kidney.

Q5

What are the tests that will tell us about kidney function?

Once we know that kidney function has to be measured, it is natural to want to know which tests should be done.

- *Blood test:* Serum creatinine
- *Urine test:* Urine routine microscopy and urine protein/creatinine ratio
- Blood pressure with an appropriately sized cuff

Serum creatinine is the blood test that tells us about the ability of the kidneys to excrete creatinine which is used as a marker for excretion of other substances. However, it is important to remember that the normal values for serum creatinine are different for adults and children. Children are smaller with smaller muscle mass and, hence, should have a lower creatinine value than adults. So, though the normal range of serum creatinine may be given as 0.6–1.2 mg% on most reports, this will not apply to children. Thus, a value of 0.8 may be quite high for a child. The kidney function in children is calculated based on the serum creatinine and height of the child and expressed as estimated glomerular filtration rate (eGFR). Without this calculation, most children with CKD will be missed.

Similarly, as explained earlier, persistent excretion of protein in the urine is a red flag for evaluating kidney function. Unless one actually measures the amount of protein in the urine, one is not likely to realize that large amounts of protein are excreted in the urine.

Of course, one should know that a single value of both, creatinine and the urine protein do not always mean a kidney problem. Sometimes conditions such as infections and dehydration can affect the values and hence if abnormal, they need to be repeated later to ascertain whether they are normal or abnormal.

Finally, a blood pressure measurement with an appropriate cuff is a must to complete the tests for kidney function. A high blood pressure may not cause any symptoms but by itself can lead to kidney damage in the long term.

Q6

So what tests are needed for our child who is having chronic kidney disease?

Your child who has been diagnosed with CKD will need certain blood tests and scans. These tests will help in finding out the reason for kidney disease, the severity of kidney damage and the presence of other problems associated with kidney disease. For example, blood tests can help in detecting if the child has less blood production and weak bones that are usually associated with CKD. Scans would be necessary to study the kidney number, position, size, quality, urinary tract, and also to evaluate the heart function.

Q7

Can my child's kidney function recover with medicines?

Just because the word, kidney failure is mentioned, it does not mean that there is a need for immediate dialysis. As explained earlier, if picked up early, only simple care and medicines should suffice (**Fig. 4**). Medicines, in the form of tablets and syrups are given to control the process of damage to kidneys and to ensure that essential elements are supplemented to the child. In early stages of CKD, there will be a need for a fewer medicines and as the severity of disease increases your child will need to take many medicines. These medicines are basically given to improve blood production, help the bones to remain strong, improve growth of the child, control the blood pressure and heart function, control protein leak in the urine, neutralize the acid accumulation in blood and sometimes prevent recurring urinary infections. Some of the measures (adequate control of blood pressure, protein excretion in urine and neutralization of acid accumulation in blood) can retard the progression of CKD.

CKD can be divided into five stages depending on the severity of damage in the kidneys. In stages 1 to 3, the child would need to take medicines, appropriate diet, and ensure that the immunization schedule is complete. From stage 4 onward, the child will need much more care besides just taking medicines. Special injections to maintain blood production and growth may be prescribed. It is usually only in stage 5, when the kidney function reduces to a minimum, that dialysis treatment will be required to sustain life.

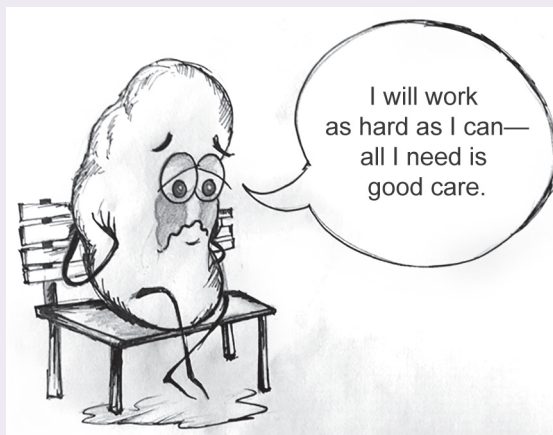


Fig. 4: Kidneys can be protected with medications in early stages of CKD

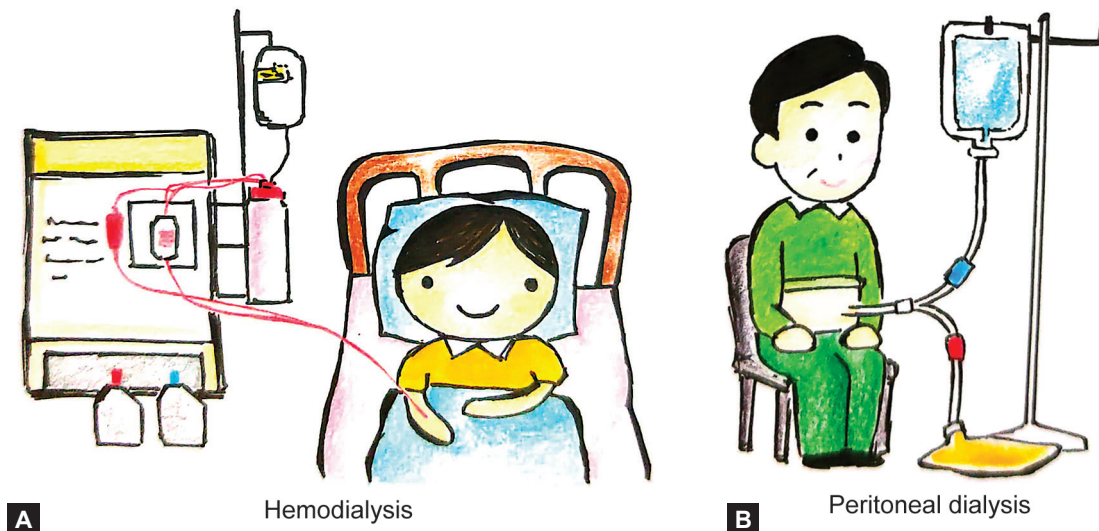
Q8

When will we know that our child needs dialysis treatment? For how long is dialysis needed?

Only a proportion of children with CKD will progress to end-stage kidney disease (ESKD). Your child needs dialysis when he or she has reached the last stage (stage 5) of CKD or also called as ESKD. This is the time when about 85– 90% of the kidney function is lost and kidney function has to be supported artificially to sustain life and get rid of all the waste products that accumulate in the body. Common symptoms that need dialysis therapy are persistent nausea and vomiting, anorexia, fatigue, breathlessness, swelling of the body, and poor growth of the child.

There are two types of dialysis: one is called “hemodialysis” and the other “peritoneal dialysis”. As you can see in **Figure 5A**, hemodialysis is a method of purifying blood by removing the waste products from the body through a machine. This treatment is undertaken in the hospital for nearly 4 hours on every alternate day. This method of dialysis needs a tube to be placed in a blood vessel around the child’s neck or groin for blood circulation and purification through the machine.

Peritoneal dialysis is the more child-friendly method as it does not need a machine, does not deal with blood, and most importantly can be done at home. In this method, a tube is inserted into the abdomen of the child and dialysis is done using a special fluid dialysis fluid as seen in the **Figure 5B**.



Figs. 5A and B: Two types of dialysis: (A) Hemodialysis; and (B) Peritoneal dialysis.

Q9

Can my child lead a regular life while on dialysis? Are there going to be restrictions to the diet?

The kidneys work round the clock and dialysis mimics the normal kidney functioning. Dialysis will help to make your child feel better by removing the waste products, extra fluid, accumulated acid, and help many of the problems due to kidney failure by maintaining safe levels of chemicals in the body and improve blood pressure control. Your child can lead a normal life while on dialysis. He/she can attend school, play with friends, and travel. Home peritoneal dialysis timings can be adjusted to suit the needs to the child and the family.

The word “kidney problem” promptly makes one refrain from all kinds of food that the child likes to eat. This is not always true and a proper dietary advice based on the stage of CKD is essential.

Common Kitchen Do’s/Don’ts (CKD for CKD)

*“When the kidneys fail a bit
Eating all things is still fit
Keeping children active and growing the ultimate hit!*

*When kidneys fail a lot
“White” things are a clear not
Red meat, fruits, and coconut water should stay away from their pot!!*

White things: Milk, milk products such as cheese, butter, etc. to reduce phosphorus, salt to keep hypertension under control, excess sugar to prevent long-term damage to blood vessels.”

As given above, if the kidney failure is mild, we do not really need to restrict anything as growth is of paramount importance in children. In moderate and severe kidney failure, restrictions will apply. Coconut water (always brought to someone who is ill) and fruits such as banana, papaya, mango, dates and raisins are curtailed because of potassium being high. Red meat and excessive protein intake may also have to be reduced. A dietitian will provide good guidance regarding nutritional requirements and about food intake for such children.

Q10

Is there any better treatment available besides lifelong dialysis?

Dialysis is a bridge therapy which mimics normal kidney functioning to ensure children stay healthy till a kidney transplant is done. The definitive management in a child with kidney failure is transplant. It is considered the best treatment because quality of life and survival is better than that of dialysis.

Kidney transplant is a surgical procedure to place a healthy kidney into a child's abdomen to take over the job of a failing kidney (**Fig. 6**). Transplantation offers a long-term solution that gives the prospect of improved health, freedom, and a more normal life.

The donor kidney can come from two sources:

1. Live-related donor—the best donors are family members, especially parents who provide a close genetic match.
2. Deceased donor—the kidney could also come from someone who has recently suffered brain death. A child can be registered in a program where they can receive a kidney from a person who wishes to donate their kidneys after death.

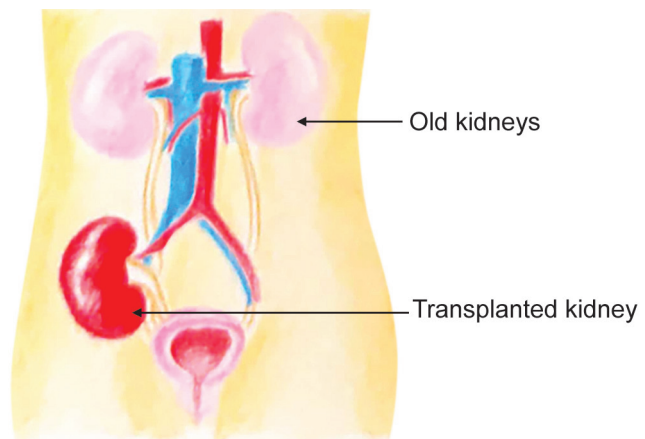
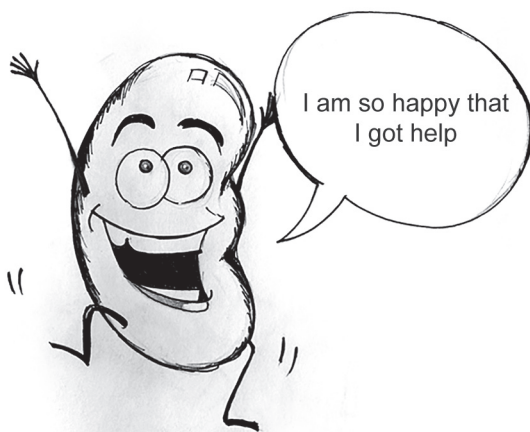


Fig. 6: Kidney transplantation in a child suffering from CKD.

Q11

Can I donate my kidney to my child? How long will the new kidney work in my child?

You most definitely can. A parent is usually the best match for the child. If you have no pre-existing medical conditions and are willing to donate, you will need to undergo several tests to determine if you and your child are compatible. If you are found to be compatible, then a team of doctors will extensively review the health of your kidneys and possible long-term effects to ascertain that you are eligible to donate. Donors are able to lead normal healthy lives with the single remaining kidney. Post-transplant, your child will need to be continued on medications lifelong to make sure that the kidney is well accepted.

Most transplants are successful and last for many years. The exact duration of how long a kidney will work varies from person to person and the type of donor. Living donor kidneys last longer than those from deceased donors. An average duration of survival of a transplanted kidney is around 15–20 years and a second transplantation thereafter is an available option. Kidney transplantation is the only way to gift your child with a second life!