Chronic Kidney Diseases and families

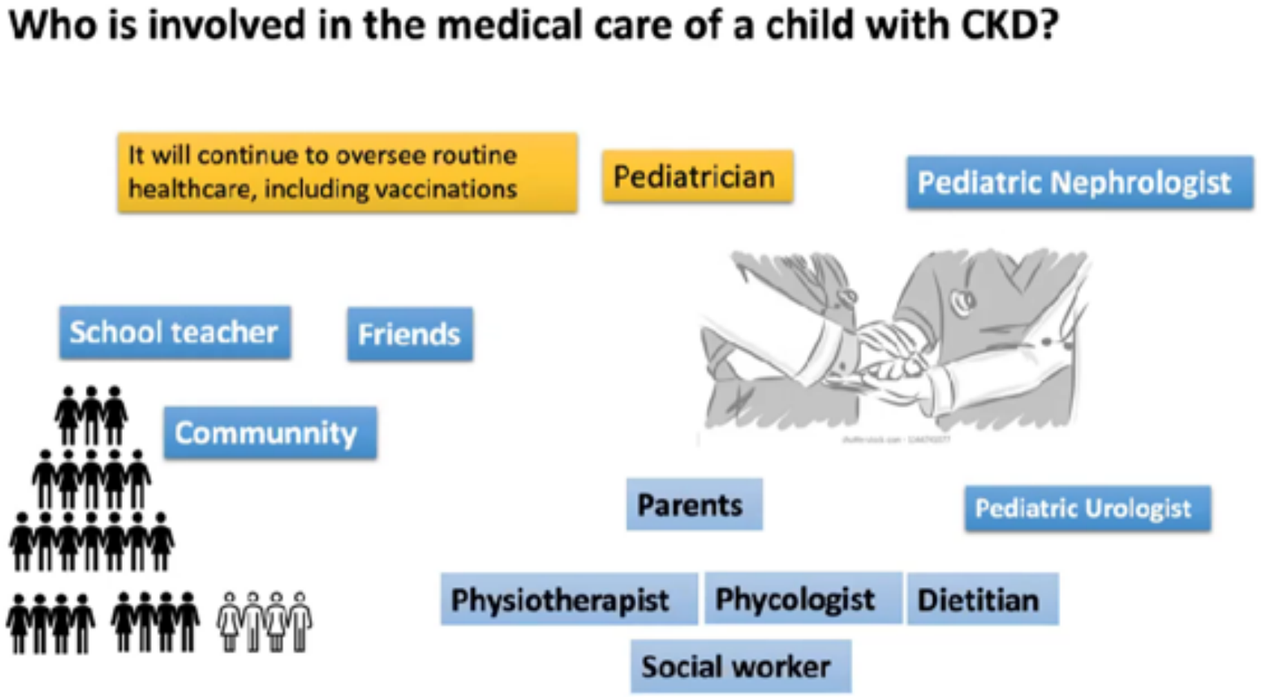


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How can CKD affect children and families?

The stress of living with a chronic disease may cause negative self-image and relationship problems. Also, the impaired brain development (reduced removal of wastes in the body can slow down nerve and brain function) may translate to learning and behavioural probles, dificulty in participating in school activities, concentrating deficit and slower attainment of language and motor skills.

There are many challenges to face: fitting in at school, graduating from high school, going to university and finding a job.



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The most common cause of CKD in infants, children and adolescents are:

- Congenital anomalies of the kidney and urinary tract (CAKUT)
- Inherited nephropaties suchs as polycystic kidney disease
- Glomerulopathies that usually appear in adolescence.

In Europe, about 500 children and adolescents present with end-stage renal disease each year.

What are the common symptoms of CKD?

In the early stages they may be asymptomatic. Growth failure (about half of children with CKD may not reach adult height within normal limits), chronic poor appetite and nausea, frequent high blood pressure headaches, swollen eyes, swollen feet and ankles, frequent urination or, in children older than 5 years, nocturnal enuresis or nocturia, rickets, bone deformities and bone pain, fatigue and concentration problems, and dry itchy skin.

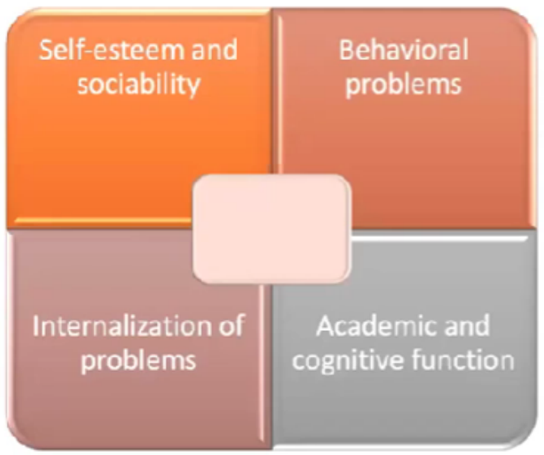
How is CKD treated?

CKD is considered permanent kidney damage that cannot be cured.
However, the goal of medical care for children with CKD is to slow the progression of the disease and complications.

- The main goals of treatment are:
- Treating the condition that may be causing the CKD,
- Relieving the symptoms of CKD,
- Slowing the progression of CKD by reducing aggravating factors,
- Proper nutrition and medications

Ultimately, almost all children with end-stage renal failure eventually receive a transplant. If a living related donor cannot be found, dialysis may be necessary until a donor kidney becomes available.

Psychosocial profile of children with CKD



Clementi et al, Pediatric Nephrology (2020) 35:767–775

The psychosocial profile of children with CKD includes: low self-esteem and sociability problems, behavioural problems, internalisation of problems and low cognitive and academic function. Therefore, there are some challenges to address: fit in at school, deal with low self-esteem, making Friends, being physically active or follow their treatment regimes.

Self-esteem: we must empower children by giving them control and responsibility over their own care as much as possible. They can learn about their medication or, if they are on dialysis, they should be encouraged to be an active part of their treatment. Parents or guardians should allow children to participate in making decisions about their treatment.

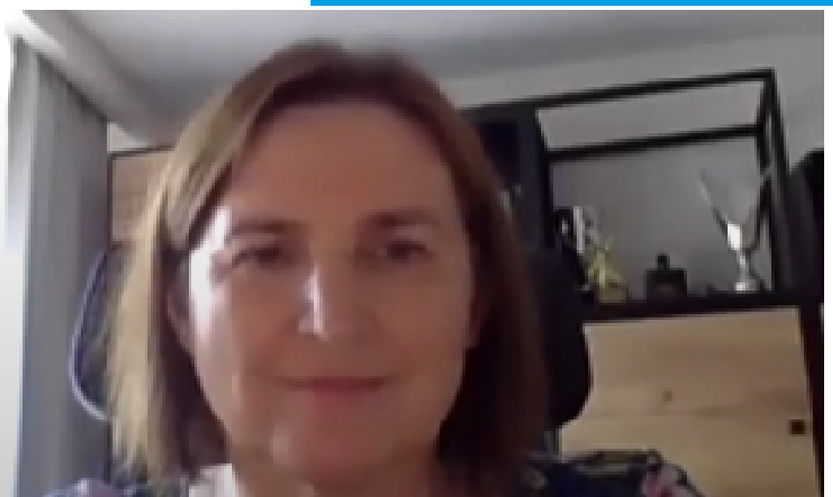
School attendance: Cooperate with the school administration. Teachers and classmates should be educated and informed about CKD and its effects.

> Pediatric nephrologists try our best to transit our patients the best way. There are pilot studies to investigate what is the best transition model, but it is still a very underinvestigated area.

Making friends: Children with CKD may face problems fitting in with their peers because of their small stature or delayed mental development. For children who have a transplant, the side effects of their medications (such as full face, weight gain, acne or facial hair) may make it more difficult to make friends.

Participating in physical activities and sports is very important. Children should be encouraged to participate in these, including exercise and sports, as it has been shown to have physical and psychosocial benefits. Parents or guardians may feel very protective of their children, but should not attempt to limit their activities unless instructed to do so.

Follow their treatment regimens: Children with CKD may have to take multiple medications and eat a specific diet. Many children may have problems with this. Adherence can be improved with a combination of health education, motivational techniques and behavioural skill methods.



Dorota Drozd
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(European Society of Pediatric Nephrology.)



Tess Harris
President of FEDERG (European Federation of Patient Groups affected by Rare/Genetic Kidney Diseases)

Families face many burdens when dealing with a child with CKD:

Financial challenges: it can be very difficult. One parent may have to stop working in order to care for the child, as it requires a lot of time. This means that the disease changes the life of the whole family. In addition, there may also be healthy siblings who feel left out because the child with CKD requires so much time and care. This is a challenge that families have to face.

Family challenges: my experience, in families where children with CKD are treated as healthy children and are taught to follow rules in the family unit, they have fewer problems afterwards and are perfectly able to take responsibility for their disease and to study and find work. In families where children are overprotected there tend to be more problems, especially during adolescence.

Health care challenges: there should be a program to prepare the children but also the family to this different type of care. In adult centers, there is no possibility of receiving the same care as in pediatric centers and this can be very difficult for the family and children. We should try to reach a common model of transitioning.

The challenge of transition: there are many associated problems. It can be a shock for families. Especially when, after a transplant, they return to dialysis in adulthood. The latest guidelines are from 2011. In 2019 they were reviewed and surveys were done to ask about the transition models that centres were implementing to discuss barriers and obstacles. There were some examples of good practice, but there was a lack of inconsistency in implementation and the biggest barrier was resources. This is something that really should be brought to the attention of policy makers in Europe to ensure that children are having the best possible transition.

Another problem to consider is the **lack of coordination**. Normally, they will not only see a nephrologist, but also other specialists such as a physiotherapist. This means a lot of coordination on the part of the families, and they have to do it themselves. This is a cost burden and also a time burden. They struggle with sorting out all the appointments, dealing with the different hospitals and the communication between them. Most parents, usually the mother, do this on their own and this can be a physical and mental burden and a frustration.

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