

Challenges for patient/family when returning to primary school with kidney disease

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Transitioning back to school can be particularly difficult for youth with chronic illnesses. Whatever the reason for returning to school (e.g., transitioning back after remote learning, a hospital admission, or summer/holiday vacations), “it pays to be prepared.” To promote proper preparation, our team at Nationwide Children’s Hospital, consisting of a nephrologist (Dr. John Mahan), a pediatric psychologist (Dr. Anne Dawson), an early intervention specialist (Elise Dawkins), and two K-12 intervention specialists (Lisa Wilson and Kat Harrelson) collaborated to answer common questions asked by parents as their child prepares to return to primary school.

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Preparing the School

Preparing the Teachers

You are your child’s best advocate. You should feel encouraged to keep your child’s teacher updated with your valuable knowledge and insights to prepare your child to return to school; if you do not feel encouraged this is a concern! Teachers in primary school play a central role in your child’s development and can serve as wonderful allies in ensuring your child transitions back to school well and is appropriately monitored.



How do I tell my child’s teacher about my child’s medical concerns?

Stick to the basics. It may be surprising to learn that many adults do not know the basics of kidney functioning. You may need help with these explanations; we also encourage you to ask your child’s medical team to help inform the teacher/school about your child’s illness, associated risks, warning signs, important infection prevention, and medication effects.



How can the teacher help with my child’s transition back to school?

Teachers often incorporate structure and routines into school days to ensure consistency. Request a copy of your child’s daily schedule to proactively address times or transitions during the day when your child may need additional support. Provide the teacher with clear information about your child’s dietary restrictions in the event of classroom celebrations with treats/snacks (e.g., birthday celebrations or holidays). Encourage the teacher to keep an eye out for any subtle mood or behavioral changes in your child. These simple steps can have a big impact on how well your child can integrate and enjoy school alongside peers and equip teachers to better care for and monitor your child.



Preparing the School Nurse

Before returning to school, make sure the school nurse and school health aide are up-to-date with your child's medical concerns and current medications. The school nurse can serve as a strong advocate for your child's healthcare needs and a good relationship with the school nurse/health aide can help ease your child's medical-related anxieties.



How can the school nurse help?

Contact the school nurse prior to your child returning to school. Have a "release of information" completed to allow the school nurse to speak with your child's medical providers. Your child may enjoy having a special meeting with the school nurse to establish the nurse as an ally. Make sure the nurse understands: 1) medical warning signs (e.g., dizziness, puffiness/edema, smell to urine, blood in urine, fever, and behavioral changes); 2) medication schedule, including timing and dosage, and any rescue medications; and 3) any diet or fluid restrictions.

Psychosocial Needs

Having a chronic illness is part of your child's life. School personnel want to be aware so they can help your child cope appropriately with her/his illness and also pay close attention to social, mental and behavioral health needs.



How do I talk to my child about returning to school?

Ask your child open-ended questions about returning to school so that he/she knows it is a safe topic to discuss. Brainstorm and role-play how your child may want to answer questions posed by teachers (e.g., how are you feeling?) or peers (e.g., why do you go to the doctor?).



How do I support my child's transition and anxieties?

If your child describes or shows anxiety, discuss ways he/she has demonstrated bravery in the past and create a bravery plan. Praise your child often for demonstrating bravery. Include the school counselor into these discussions early. Your child may also benefit from meeting with a pediatric psychologist if you have concerns with coping, adjustment, or any mood/behavioral changes.

Basic School Business

Chronic medical illnesses are considered a disability. Students with disabilities are required to attend school in person if reasonable accommodations can be made under the provisions within the Americans with Disabilities Act.



What are the steps to ensure readiness on return to school?

Complete all appropriate "Release of Information" forms so your child's school and medical team can share important information and reduce your role as the "middle man."

Formally request any accommodations your child may need to succeed in school. Your child's medical team can also advocate for appropriate accommodations.

A 504 Plan, created in collaboration with school staff, can include medical (e.g., access to a water bottle, breaks from physical education, unlimited toileting opportunities) and learning accommodations (e.g., extended time, frequent breaks, smaller setting for tests).

If additional learning supports are needed, you can initiate an evaluation for an Individualized Education Plan (IEP). A parent must request an evaluation in writing and the school has 30 days to respond to any request.

Additional resources to help you navigate this process:

1. Your state's education department website
2. <https://www.understood.org/>
3. www.fetaweb.com

