

"So You Want to Be a Pediatric Renal Social Worker..."

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A NEW LIFE; A NEW CHALLENGE

When a baby is born, parents look for 10 fingers and 10 toes. Few ask specifically if the baby's kidneys are working. When problems are diagnosed within the first few days, Mom and Dad spend what they had anticipated as initial happy moments in a neonatal intensive care unit (NICU) instead. The moments are filled with fear and guilt and with questions that are not always easily answered for them.

All the dreams and hopes that developed over nine months are frozen in place. All the expectations are on hold, and fear and worry take over. The loss of those happy times can wear on a couple. If there were issues prior to the birth, these issues will surface and demand attention. If there are older siblings, Mom and Dad struggle to provide care for them, answer their questions, and shield them from the fear.

CASE STUDY: KEVIN, AGE FOUR MONTHS

Kevin was diagnosed in utero. His mother was referred to the pediatric nephrologist during her pregnancy. She was aware of the difficulties and felt initially that she was prepared for Kevin's NICU stay and need for dialysis.

She and the father had a tenuous relationship, which unraveled during the pregnancy. He did not attend the birth and tentatively visited his son in the NICU following a confrontation with mother. Alternate visiting times were set up, which reduced some of the nastier encounters.

During the eight weeks in the NICU, Mother breast fed, rocked Kevin, and took in as much information about her son's medical status and needs as she could. Mother trained to do the peritoneal dialysis and did quite well. With the social worker's recommendation and assistance, she prepared her three older children for Kevin's homecoming. The social worker addressed concrete issues and plans for how this single mother of four was going to maintain her career as a CPA.

During the last two weeks of hospitalization, Dad decided that this was his only son and he needed to be a part of his life. Not a good plan as far as Mother was concerned. She had begun to understand just how much time and work it was going to take to care for Kevin.

She tried to talk to Dad about this, but he interpreted the discussion as Mother's way of trying to get him out of the picture. So, she turned to the treatment team.

A conference was set up with Dad. During this conference the nephrologist, PD nurse and social worker attempted to explain Kevin's medical needs. Dad's focus was on visitation and his father's rights. The team supported his desire to see his child while explaining that training one parent to manage the PD was a means of reducing the opportunities for infection. Dad said it was required that he be able to take his newborn, PD-dependent infant to his own apartment at least three to four times per week for up to eight hours. All attempts to educate him regarding the difficulties in this plan went unheard. At a court hearing that same week, Dad was able to gain four days of visitation at the Mother's house. Within two weeks of Kevin and his mother being discharged home, Dad and Mother had difficulties with this plan, which resulted in the father calling the police on two occasions. Both attorneys contacted the social worker, as had been recommended by the nephrologist prior to Kevin and his mother's discharge from the hospital. The attorneys had difficulty understanding Kevin's needs and their ability to advocate for their clients was stymied. The social worker also recommended that a guardian ad litem be appointed for Kevin, given the issues between Mother and Dad. Both attorneys thought this was a good idea. Dad was unsure of the idea, but Mother supported it wholeheartedly.

When Mother brought Kevin in for a routine biweekly weight check, she was clearly not coping well. The PD nurse and dietitian contacted the social worker immediately. During the visit, Mother reported that she had lost 15 pounds, was struggling with trying to adjust her schedule, and was concerned about Dad's visits. Dad did not understand that placing his son on his tummy was not a good idea. He argued with Mother, insisting that this was the way he had been told to do it by his mother. Mother had asked him to work with the PD nurse so he could better understand Kevin's medical needs, but he never got around to doing it. The social worker suggested that Mother and Dad come in with their attorneys to see the treatment team during a routine PD visit. This was an attempt to get everyone on the same page with a consistent plan in place.

Everyone arrived on time for the PD visit, and the nephrologist proceeded to go through the routine questions and to make the necessary changes to keep Kevin on track medically. Kevin had grown a little and had put on a tiny amount of weight, all good signs of Mother's hard work in caring for her newborn. Dad understood very little of what was going on, as he did not know much about Kevin's medical status and kidney disease. When Mother requested that the number of visitations be reduced, as they caused her serious stress, Dad's attorney refused to negotiate. The team tried to explain the seriousness of Kevin's status and the need for consistency and reducing opportunities for infection. Mother requested that Dad come to all medical visits. She suggested using these appointments as one of the visitations. He agreed to do this. The social worker made arrangements to see Mother, Dad and Kevin on a weekly basis until the attorneys could work out a better plan. The dietitian offered to do weekly weight checks and the PD nurse indicated she would see Kevin as well. But the work has just begun in caring for Kevin. The treatment team knows that there will be more challenges in the future.

Pediatric treatment teams see these patients and their parents on a routine basis. Creative management demands that each member of the team understand the broader picture. In this case, Mother and Dad have a long way to go before they can work together for Kevin. Both are dealing with issues of loss, anger, and disappointment: for themselves, their own relationship and their son. It is important for the social worker to provide the opportunities for these parents to address their issues and concerns. If they are not resolved, the treatment team will see the signs: poor medication maintenance will show in lab work; missed appointments will increase; and attention to details will no longer be evident in overall care.

TODDLER'S TRIALS

If the social worker intervenes early in the diagnostic and treatment process, parents can use the systematic approach to problem solving as a format by which they address the inevitable issues that arise in caring for a pediatric CKD patient.

If the diagnosis of CKD comes during babyhood, questions about what was done wrong or what was missed are often the initial response. Parents want to know why the pediatrician did not know about the problem sooner and why they did not recognize symptoms. Between

keeping the baby comfortable, watching the baby endure the testing and blood draws, and trying to hear everything the doctor, the nurse, and the dietitian are trying to explain, parents often shut down despite themselves. That's when the social worker is essential to the care of the baby and the family. The initial intervention that is done by the pediatric nephrology social worker makes it possible for the family to make decisions that will only be the beginning of a lifelong journey.

CASE STUDY: KAT, AGE 2.5 YEARS

Kat is an undisciplined child who appears to have enough energy to run the world in her spare time. She was referred after it was discovered during a visit to the pediatrician's office that there was protein in her urine. It was a routine referral to the specialist. Mother did not initially take it seriously when it was first found, over nine months prior to our seeing this child.

Upon entering the exam room the social worker encountered a child who was climbing all over the furniture, exam table and making a serious effort to conquer the higher counters. Her mother, who was five months pregnant and had little energy for dealing with her daughter's behavior, was sitting watching the child conquer the room. She readily admitted this and asked that the social worker try to help her figure out what to do. Pediatric renal social workers see and hear this on a daily basis: a 19-year-old mother, unprepared for motherhood. She admitted that she wanted children but it had all happened too fast. Kat's father became scarce upon learning that the mother was pregnant with Kat. She did not have the money for prenatal care, so she did not see anyone until she went into labor at the county facility. Now her child must be monitored, as she has been diagnosed with nephrotic syndrome and hypertension.

The frequent clinic visits, which also require either a urine sample or a blood draw, are very difficult on Kat and her mother. Mother has difficulty seeing and hearing Kat object to the blood draws to the point that she has asked that one of the staff hold Kat for this procedure. She cannot get a urine sample at home so this is also part of the process. Mother tries to understand what the nephrologist is explaining regarding Kat's disease and difficulties but has told us all that it is more than she can take in. The social worker has developed a relationship and participates in the clinic visits. Despite the nephrologist's efforts to explain the medical issues as clearly and simply as possible, the social worker has noted that mother appears to listen but does not really hear what he is telling her. That blank look says it all.

The social worker has been able to take small pieces of information that Mother needs for Kat and interprets them for her. This has increased Mother's understanding that she needs to keep the clinic visits and to fill the prescriptions. She doesn't really understand what the medications do, but she knows that without it, this child blows up like a balloon. She also understands that Kat's behaviors have been influenced by the medications. Unfortunately, she uses this as an excuse to avoid disciplining Kat. The social worker is still working on that one.

Mother has begun to verbalize that caring for Kat's nephrotic syndrome will take vigilance on her part. With the help of the social worker, she has been able to arrange for respite care so she can go to parenting classes. She has begun to see a family support specialist through the state-funded mental health program and she has kept all of the appointments made for Kat. Mother talks freely with the social worker about how the new baby will take even more time and how frightened she is of all the responsibilities. She worries that the new baby will have the same problems. With education, counseling, and appropriate systems support, this mother has an opportunity to provide good parenting and to participate effectively in her daughter's medical care.

CKD KIDS GO TO SCHOOL

If the diagnosis is made in a school-age child, additional components are added to the picture.

To this point, there has been the child, the parents, siblings, extended family, the family pediatrician, and the CKD treatment team. Now teachers and peers, cafeteria choices and physical education issues, and missed school days are added to the stress index. Parents begin to worry about how well the child is learning. The social worker addresses growth and development concerns on a routine basis. It is important to keep a CKD youngster in school. In order to do so, the social worker must address the child's emotional responses to the diagnosis, the manner in which the child is being parented, the teachers' response to dealing with a child who does not necessarily look sick (like someone with leukemia), and the doctors' appointments that take away from instruction time. Add to this the challenge of a child on dialysis who must learn how to navigate the American school systems' cafeteria choices. So the school system, with all of its requirements, expectations and restrictions, enters the picture.

CASE STUDY: ALEX, AGE 10 YEARS

Alex is on peritoneal dialysis. He was hospitalized in the summer, during which he had his catheter placed and his mother was trained to put him on PD every night. They did well for the remainder of the summer, but now that school has begun Alex is having his difficulties. He has an older brother and two younger sisters. His older brother began middle school that year and was not available at their elementary school. His two younger sisters were just beginning school. Alex was returning to a familiar school and some of his friends from the previous year. He had a new teacher and a new school nurse.

Every morning Mother must get Alex off his PD, all of the children ready for school, feed them, and get herself dressed and ready for work. She was struggling with the schedule but Alex had only been tardy twice. Mother had asked the social worker to work with the school so they would all understand that Alex had some special needs. The social worker called the school nurse, looked into an IEP (Individual Education Plan), and had the doctor complete the chronic illness forms that would allow the routine absences for the monthly PD clinic visits.

About five weeks into the first quarter, Alex's teacher called the social worker, asking how long he would be hospitalized. Since Alex was not in the hospital, this came as more than a surprise. The social worker called the home to find that mother was unaware of Alex missing any school. An investigation ensued.

Alex and his sisters took the school bus every morning. Upon reaching school, Alex went in one direction and his sisters in another. He spent the day in the neighborhood, but had been able to avoid detection. He never did share how he did this. When he saw the school buses line up to take the children home, he made his way onto the campus and simply got on the bus to go home.

When the social worker spent time talking to Alex, he shared that his best friend had asked him about the tube in his belly and then did not want to play with him anymore. He also had trouble in the cafeteria because he couldn't eat the food: cheese enchiladas, macaroni and cheese, and hot dogs. And he hated going to the school nurse to get his medications. The physical education teacher wouldn't let him play dodge ball, so he had decided that going to school just wasn't worth the effort. The social worker assured Alex that these were

problems that she could help him work out if he were willing to do so. She worked with his mother to better understand the changes and concerns that Alex was experiencing, despite the fact that he was not telling her about them.

A visit to the school was made, which offered the school nurse, teachers and physical education coach an opportunity to voice their fears and concerns. Alex thought it was a good idea for the social worker to help him talk with his classmates about his PD. This proved very helpful, as many of them had questions which, when answered, allowed them an opportunity to tell Alex that they cared about him and wondered what they could and could not do when playing with him.

Alex returned to school and has done well since.

The social worker who is available to problem-solve with the child, the family and the school system has a direct impact on that child's educational future. Children can be very accepting of new things but are frightened of things that adults do not want to talk about with them. Once the conversation with his classmates started, Alex and the social worker were able to deal with some amazingly sophisticated questions. Too often we adults underestimate children.

TEENAGERS...WHAT CAN BE SAID?

When the child is diagnosed with CKD in adolescence, adherence to treatment regimens and medication compliance can become a battleground. Unless they clearly understand the disease process and the consequences if recommendations are not followed, parents can be as much a detriment to care as the adolescents themselves. The social worker often deals with these kids and their parents. Lab work that is indicative of issues with parental monitoring and adolescent nonadherence are issues dealt with by the treatment team routinely. In the pediatric setting the social worker is seen as the active team member. The social worker assesses the patient and family, validates and supports the strengths, instructs and counsels on how to address the areas of concern, and monitors progress. Sometimes the social worker mediates between the teen and the treatment team.

CASE STUDY: BEV, AGE 16 YEARS

Bev's diagnosis came as a complete surprise to her and her parents. She had gone to her pediatrician for a routine history and physical in order to play basketball for her high school squad. Within a few short weeks of that

visit, nothing in Bev's life was routine. She chose to go on hemodialysis, as she did not like the idea of a tube coming out of her tummy.

Her parents tried to maintain their routine and to manage the stresses of this situation, despite all the difficulties. They did not want this problem to make any major changes in their lives, believing that this was the way to normalize the diagnosis. They wanted Bev to take responsibility for her medications and to watch her diet. They insisted she keep all of her honors classes and asked that we have the hospital teachers work with her while she was on hemodialysis so she could keep up.

Bev tried her best for the first quarter of school. She arrived on time for her dialysis, worked on her school assignments, took all of her medications as prescribed and ate only what was best for her. However, by the end of that quarter she was withdrawn and moody. She rarely smiled and did not want to interact with the hemodialysis nurses. She did not want to get to know any of the other kids on hemodialysis and avoided all activities in the unit.

The social worker noticed the changes and made time to talk with Bev. Expecting to meet resistance, she was surprised at how quickly Bev was willing to share her fears, concerns and anger. She admitted that she "played" with her meds and didn't try very hard when it came to her honors math and science classes. She shared that her father tried so hard to avoid dealing with the diagnosis and treatment that she felt like a "weirdo."

The treatment team became frustrated with Bev and her parents. They saw Dad as uncaring and rigid. They saw Mom as distant and cold. The social worker met with the parents and was able to help them deal with the loss, guilt and anger they were working so hard to avoid. Bev and her parents were able to joke about the "dialysis machine under the living room carpet" and to start to talk about the future.

After consistent education and counseling, the social worker was able to help this teen and her parents realign their priorities, understand how to incorporate the medical regimen into their daily lives and focus on planning for transplant. The social worker worked with the treatment team to see the parents in a different light.

ADULT OR "BIG" KID

Most of the young adults that the nephrology social workers care for have been diagnosed sometime prior to this stage of their lives. Consequently, the issues that surface are ones that have had the time and practice to be problematic. Young adults crave independence. On the other hand, some are so dependent that they do not want to be responsible for anything and leave all responsibility to their parents. Parents accustomed to years of worry and vigilance find letting go difficult. And some parents are so weary from the long battle that they surrender under the stress.

Pediatric social workers attempt to mediate, instruct, and counsel in these cases.

CASE STUDY: HANNAH, AGE 19 YEARS

Hannah has had two kidney transplants. Her mother donated the first kidney when Hannah was 15. Despite parental vigilance, she lost that kidney when she was 17. When it was suggested that they go home and try to locate the immunosuppressant medications following her emergency admission to the hospital for rejection, they returned to confront Hannah with the hundreds of pills that she had hidden between her mattress and box springs.

Following two years on dialysis, Hannah was ready for another transplant. The transplant team agreed that the therapy work she had been doing had made significant changes in her level of responsibility and understanding about what was needed for future transplant success. Hannah and the social worker had identified issues, set goals, and worked on preparing Hannah for a successful second transplant.

Her father made the donation this time. As she recovered, Hannah started to make plans to complete her education. She wanted to become a teacher. She had been

researching colleges on the Internet and had decided on a small college in a smaller city about 100 miles north of her home. Mother and Father were not happy. They both feared that, without their constant supervision, Hannah would lose this kidney. They worried constantly that Hannah would not follow through with medications, would "go wild" over boys and would not be able to do the class work.

With counseling, both Hannah and her parents were able to agree that she could manage this life transition with their support. They were willing to try to step back a little and allow Hannah the opportunity to experience the normal failures of a young adult.

COMMENTS

There are few places where social workers have the level of access to so many people under such ripe circumstances as in a kidney treatment situation. Pediatric renal social workers listen, assess, counsel, advocate and educate. They are the first line of defense that addresses the cyclic issues presented in emergency rooms, outpatient clinics, hospitals, and doctor's offices. They have an opportunity to positively impact the way a family grows and develops.

The pediatric renal patient will live longer and will become the adult patient of the future. What we as pediatric renal social workers do now will impact that future. And what we do will also have an impact on the adult social worker who will care for our patients when they are adults. That is why it is so important for both the pediatric and the adult renal social worker to understand the intricacies of patients who start their journeys at birth or during childhood. What patients learn as children is what they will do when they are adults.

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