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Helpless to Self Reliance: A Pediatric Dialysis Patient's Story

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D.R. was born with "horseshoe kidneys". He was transplanted at age 8. He lost his transplant at age 13 due to chaotic home environment and little adult supervision. He stopped taking his transplant medications. When he started dialysis he was profoundly depressed. He is now 16 and remains on hemodialysis. He has been on hold for another transplant because of continuing family issues. The pediatric dialysis team, including D.R., identified the following needs:

1. Compliance with medication protocol.
2. Need for psychiatric intervention for depression.
3. Dietary compliance, specifically Calcium and phosphorous with a product of 120 and higher.
4. Calcyphilaxis secondary to #3 resulting in calcium deposits in both ankles and feet causing severe pain and inability to walk. Also surgical revision of his fistula due to calcium deposits causing narrowing of the fistula.
5. Loss of educational time at school.
6. Weight loss secondary to depression and lack of funds for healthy renal friendly foods.
7. Social work involvement with the family.

Some of the interventions and outcomes:

1. Dan was asked to bring his medication bottles in each treatment to go over his medications, explaining doses, reasons for the meds and side affects. He can now explain all of his medications. He needs to be self reliant with this because of his family situation.
2. Dan has been seeing a psychiatrist and counselor. He is on medication for his depression and is being monitored.
3. Our team has phone conferences periodically with the county Intensive Management team to discuss the families needs as well as Dan's. This was implemented through CPS after they were notified by our team of the family's need to more support.
4. Several team and school team meetings have been held to educate the school about dialysis and come up with strategies to deal with his fatigue, poor mobility, depression and educational needs.
5. Referral for orthotics and PT to improve mobility. D.R. now walks independently but with a slow gait.
6. Referral to the transplant team to write out a contract with the patient outlining specifically what he needs to do to be active on the transplant list.
7. Self reliance with dialysis. Dan sets up his machine, preps his arm and puts his own needles in. He is responsible for calculating his weight for fluid removal.

There are many other interventions that were successful that will be included in the presentation.

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