Unplanned Start on Dialysis: One size does not fit all!

Introduction: Unplanned start to dialysis (UPS) occurs in patient groups both known and unknown to the nephrology service. Given the high prevalence and poor outcomes associated with UPS and the lack of preparation time for those patients with education and information, our renal MDT developed an UPS pathway in 2011. The main focus was on information-giving around treatment modality decisions, access requirements and encouragement to opt, where possible, for an independent treatment modality. Despite this development we were aware that many UPS patients struggled to adjust to the requirements of their treatment; the competing demands of their health needs and work/life balance proved difficult to maintain.

Proposal: An audit in 2015 on the numbers of patients starting dialysis during a hospital admission and remaining on the chronic programme revealed two groups of UPS. The first included unknown UPS and AKI, in total 26 people. Of these 13 were late presenters previously unknown to the renal team, 5 were unknown referred from elsewhere and 8 presented with AKI. The other group, in total 30, comprised of 22 known to the team but with an unexpected decline and 8 previously known but lost to follow up as they had not attended hospital or GP follow up appointments. The total of these two groups represented 49% of dialysis starts in 2015. The main focus of the audit was on dialysis access and treatment modality outcome. We decided to review the UPS pathway to see if there were any common themes from the patient perspective. The initial UPS nurse/renal SW assessment was reviewed as well as any subsequent renal social work assessments and interventions. The renal dietitian interviewed some patients using a patient story approach discussing their views about the benefit of information given to them about their health/diet/social support.

Results: While the renal MDT was concerned with the quality of dialysis treatment, adherence to the dialysis prescription and concordance with medication and dietary regimes, predominant patient concerns raised were regarding housing, employment and financial issues. They also identified being overwhelmed with information given by various members of the MDT at a traumatic time. This approach often caused confusion and interfered with their ability to process and understand complex information and treatment choices, for example, some could not recall even being offered treatment choices. The patient view was that being given information in a more frequent, repetitive and consistent way would be more manageable and helpful and for this to continue for a longer period of time to ensure they had the best chance to adjust to their new health situation.

Outcome: The main change that we have implemented so far is for the renal social worker to meet and assess UPS on a regular basis when they attend for dialysis or via telephone follow up. Currently this is continuing for a period of at least 4 months post discharge from hospital. A person-centred and coaching approach is used and addresses the route to being an UPS, the psychosocial history taking into account cognitive ability, mental health, social support networks, employment and any stressors or triggers that may impact on quality of life. We are currently collating the outcome data.

Conclusion: UPS to dialysis seem to understand their situations more effectively if they are given information in small sections, repeated to them as many times as is necessary and checking back with them their understanding. Attention to what the patient is telling us is their primary concern will encourage engagement between the individual and the renal MDT and help to identify issues in a proactive way rather than necessitating crisis management. UPS to dialysis are automatically at a disadvantage due to the acute and unexpected nature of their start to treatment. There is still a great deal that is unknown regarding people who start in an unplanned manner and whether there are any lasting effects. Research is required regarding the risk factors, the psychological and social issues to ensure that a holistic approach is taken.