CAUSE FOR CONCERN (CfC) REGISTER: SUPPORTING ADVANCE CARE PLANNING FOR PATIENTS FAILING ON DIALYSIS

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INTRODUCTION: The advances in medical treatments have led to expectations that every medical problem can be resolved. However, when complications accumulate and options for effective interventions become limited, patients, families and staff must face difficult choices that affect the length and the quality of life. Renal teams are increasingly aware and concerned how best to support patients on chronic dialysis who are facing these serious medical decisions and when there is concern that continued delivery of conventional care alone will not meet the patient's needs. Such patients need advance care planning for the their future treatment including the phase of end of life care

PURPOSE: Despite a well established conservative management care programme we became increasingly aware of the need to address the issues affecting patients who were 'failing on dialysis.' We had struggled with the barriers and the conflicts that arose when addressing these difficult issues and whilst we had previous experience of supporting patients when a decision was made to withdraw from dialysis treatment, we felt there was a need to have a more consistent and proactive approach to support patients and staff to facilitate communication and care planning. To address this we developed 'Cause for Concern' (CfC) support register for patients identified as approaching the end of life phase.

DESIGN: Initially a steering group drawn from the multi-disciplinary team was set up. The steering group carried out a case review of patients that had withdrawn from dialysis in the previous year, and identified and discussed the end of life tools available. We devised a CfC integrated care pathway which incorporated the Gold Standard Framework (GSF), Preferred Priories of Care (PPC), Advance Care Plans (ACP) and Liverpool Care Pathway (LCP), medical and non medical leads were agreed and a link nurse in each area identified, a CfC support register was set up with a monthly review to discuss new referrals as well as those on the CfC support register. The ongoing collaboration and involvement with primary and palliative care services was an important part of this development.

FINDINGS: During the following 2 years 24 patients were identified as a cause for concern. The issues were broached with the patient and their family/carers by members of the clinical team and all were established on the register. All the patients and their family/carers were active in the advanced care planning which links to primary care and palliative care services. 17 patients subsequently withdrew from dialysis and died supported by the renal, primary and palliative care. 7 patients remain on the register but all have a plan regarding their goals for treatment and preferred options should their medical situation deteriorate further. What has developed has been a support care service for patients and family to discuss goals of care as well as to make decisions regarding the end of life care.

CONCLUSION: The creation of a CfC register has increased awareness within the team of the dilemmas and need for discussion with patients who are failing on dialysis. Patients have appreciated the opportunity to discuss their future treatment and needs, and to make decisions regarding how they wish to be managed should their situation deteriorate. Subsequent feedback from family/carers indicates satisfaction with the process of being given support from initial discussion to bereavement. The team feels committed to continue with the cause for concern pathway as we feel it has been an important and supportive model of care.