



Key Message on Self-Care Dialysis

The Kidney Alliance believes that patients should have a choice of dialysis therapies, including those which can be undertaken in their home. These treatments enable patients to care for their own dialysis and can be delivered either in the form of haemodialysis or peritoneal dialysis.

Haemodialysis has been established as a successful life sustaining treatment in patients with renal failure for over 40 years. Through a mix of financial pressures and convenience for patients, the number of hours patients spent dialysing has fallen gradually. Thrice weekly treatment for approximately 4 hours carried out in renal centres has now become the normal experience for the vast majority. Clinical and laboratory measures to ensure patients receive an adequate dose of dialysis are in place in the UK

It is increasingly recognised that conventional thrice weekly haemodialysis, which most often totals 12 hours per week, 'replaces' only approximately 10-15 % lost kidney function, and has limited impact on quality of life. Essentially patients continue to live with chronic kidney disease equivalent to CKD 4/5. More frequent treatment, particularly if the 2-day 'long break' is avoided, not only allows for a relaxation of dietary and fluid restrictions it can also deliver much more dialysis. Impressive improvements in wellbeing and measurable clinical outcomes are being reported with enhanced, frequent haemodialysis. In practice, this therapy is best carried out in the home or in a community setting by patients trained in self-care. After many years of decline, the number of patients opting for self care haemodialysis is now growing in several countries, with most patients who have opted for self-care dialysing more frequently than thrice weekly. Recently the introduction of mobile, patient friendly machines has provided new opportunities for dialysis 'on-the-move' and freedom from rigid treatment schedules.

The Kidney Alliance recognises that the NICE guideline (2002), which envisaged up to 15% haemodialysis patients at home, has created little movement and, while there are occasional examples of success, less than 2% HD patients in the UK are currently self-caring. Equally the Alliance recognises this guideline predated the benefits of enhanced dialysis now being reported from other countries. The Alliance anticipates enthusiastic uptake of frequent treatment among some patient groups, particularly using new mobile machines. With peritoneal dialysis (PD) being already established in the UK we envisage a complementary synergy with HD carried out in the community, as those already doing a self care dialysis therapy such as PD are often more comfortable moving to self care haemodialysis.

The Alliance calls on Specialised Commissioners to ensure that all patients are provided with the education and the opportunity to take up this choice in keeping with a patient centred health service, and to work with social care to implement this. An important component of success will be for the NHS to recognise that the PbR haemodialysis tariff should include set-up costs of community/home care and re-imburement for up to 6 sessions of dialysis per week in those patients motivated to optimise their health prospects to remain well and to stay out of hospital. The implementation of a new tariff for home haemodialysis, based on a weekly quantum, is broadly welcomed. However, the reference costings behind proposed tariff are not clear and the Kidney Alliance would welcome discussion on a tariff structure that does not create barriers to the uptake of home haemodialysis.

Kidney Alliance members: British Kidney Patient Association, British Renal Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, Association of Renal Managers, Royal College of Nursing (Renal Forum), British Association of Paediatric Nephrologists

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Key Message on Self-Care Dialysis contd

In particular, three aspects need addressing:

- 1) There is still not enough detail to understand the costings behind one off installation of a home HD set up and how the proposed tariff addresses these costs.
- 2) There is no discussion or costs related to the training costs for individuals and carers that may be over and above direct therapy costs.
- 3) There is still concern that more frequent regimes of therapy and newer more effective platforms may not be affordable under the current PbR structure.

The Kidney Alliance welcomes the instigation of a new home HD tariff (and also a tariff for assisted APD), but would welcome discussions with the PbR team and the Department of Health to refine and improve the model.

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