

Enabling self-management and shared haemodialysis care in hospital based dialysis: learning from the project

Key findings

- Patients reported greater control of their illness, an increase in confidence and feeling more able to ask questions about their treatment.
- Staff reported an increase in job satisfaction and greater respect for patients as they became more involved in their care. Nurses saw patients as part of the team and engaged more closely with them before, during and after dialysis.
- There was more dialogue between patients and nurses in shared haemodialysis care areas, as well as between the patients themselves.
- Some patients felt frustrated by a slow rate of progress, with different levels of engagement among staff, or because they had hoped to be able to dialyse at home but were unable to do so for logistical reasons.
- Staff were able to spend more time with more dependent patients who were not involved in shared haemodialysis care, which improved the quality of their care.

Successes

- **Impact on patients' lives:** Patients welcomed the opportunity to take responsibility for some aspects of their care and many shared compelling personal stories of the difference it had made to their lives. One patient commented: 'I was really depressed when I first started haemodialysis. However, since I've started shared haemodialysis care I actually look forward to coming for dialysis.'
- **Engaging nurses:** Patient stories played an important role in engaging nursing staff in the project and convincing them of the benefits of shared haemodialysis care. Nurses described having a 'lightbulb moment' during the training course when they realised the value of giving patients the opportunity to take part in their own treatment.
- **Passion and commitment:** Nurses and patients showed strong commitment to the project and a passion for the shared haemodialysis care approach.

Challenges

- **Ambitious scale:** Embedding shared haemodialysis care into all 26 units at the same time proved to be an overly ambitious for the two-year timescale of the project and created challenges at times. For example, during the pilot phase of the project,

some of the units who were still waiting to be engaged expressed frustration at the lack of progress they were seeing.

- **Differences across the units:** The team found it more challenging to deliver the project in units where they did not have managerial control over the dialysis service. They also experienced difficulties working with units that had low staffing levels or where there were significant competing pressures.
- **External changes:** Changes to commissioning arrangements, NHS Kidney Care and Clinical Networks created a period of uncertainty and anxiety throughout the project.

Advice to others

The project team recommends allowing a degree of flexibility about how shared haemodialysis care is delivered at different units, to accommodate different needs and ways of working. They advise making small but measurable changes, in order to motivate staff and patients.

When it comes to engaging staff in the project, the team says that the most persuasive approach is to share stories from patients about what it means to them to take on responsibility for aspects of their care. Training should focus on enabling nurses to understand, discuss and compare notes on how best to support patients, and patients' progress should be captured in an easy-to-use competency handbook.