

<b>Name /title of project and organisation</b>
Improving access to Home Haemodialysis (Home HD)
<b>Short summary of the area we needed to address</b>
Inequitable access to Home HD across the UK. Drivers for change have included patient groups, NICE guidelines and an international drive to increase the number for patients dialysing at home.
<b>What did you want to achieve with your QI initiative?</b>
Wessex Kidney Centre (WKC) based in Portsmouth, like many UK renal units had a big decline in Home HD during the 1990s. Between 1999 and 2009 there were no patients receiving haemodialysis at home and it was not an available therapy to offer patients. Due to the targets set by NICE and patient advocates within WKC the unit set about re- establishing the Home HD programme with the ultimate goal of making it a realistic dialysis option for all patients who wished to receive it.
<b>Who was involved in this QI work?</b>
The initial project to restart a Home HD programme was set up by our Community matron who was responsible for the running of the satellite dialysis units. This was supported by the management team and the Consultant lead for Haemodialysis. An enthusiastic group of nurses working in the haemodialysis units agreed to take this on in addition to their current role. The initial attempt to restart the programme using traditional dialysis machines was approved by the trust with a small capital investment agreed. Two patients were included in the initial pilot and were trained for Home HD. The first received a transplant 14 days after commencing at home, the second dropped from the programme within a short time due to technical issues. The team then began to look at other options in 2009 when the Nxstage system One was launched in the UK. After gaining agreement from the Trust the team was given permission to carry out a year long pilot study initially with one patient to trial this new technology. Subsequently the programme has rapidly grown to become one of the largest Home HD programmes in the world. WKC now has a team of 7 nurses, a dialysis assistant shared with the pre dialysis clinic for pre Home HD education and two consultants. The programme expansion, lessons learnt and barriers that have been overcome will be shared here.
<b>What did you do?</b>
In 2009 the first patient was trained for home using the Nxstage system One. WKC set out to provide an inclusive programme inline with NICE recommendations. As this was a new service within the WKC it was not predicted that it would prove to be so successful and so much of the planning and project management evolved over the course of the project. Following a pilot period the data was presented to the Trust and approval was given for a further 5

patients to join the programme and a Nurse was seconded from a satellite unit to manage the programme. Initially the programme started with a group of stable and motivated patients with good vascular access who would be fully independent without the need for a care partner. By 2011 the programme expanded further to include patients with more complex needs, the first patient transferred to nocturnal therapy and the first patient who lived alone was trained for Home HD. The lead nurse role was made a permanent post and a dialysis assistant was seconded to support her. The programme continued to grow throughout the next 3 years. During this time an area in the main unit was established as the Home HD training area. As this area was also set up for bed spaces, training was interrupted on several occasions due to demand on hospital beds. It became clear to the team that to continue to facilitate programme growth a dedicated training area away from the inpatient unit was required. This was successfully secured as the team managed to rapidly grow the programme during 2014 training 45 patients from the training area which measured just 2.4 by 4.7 meters. This area was increased in 2016 to a space 50% larger with the original area still available for use and storage.

Staffing numbers have also grown with the programme. There are no current national guidelines on the number of patients a Home HD nurse should support but it became very clear in the WKC programme that once that number exceeded 20 patients per nurse the patients reported feeling unsupported and there was a clear increase in patients stopping therapy for this reason. As a result of this the business cases for further nurses was approved with the aim to maintain the nurse to patient ratio below this level to ensure adequate support but also to allow additional staff to continue training. We have now set a limit of 15 patients to one nurse as all the Home HD nurses also train patients.

During 2014 the first patients were trained from pre dialysis clinic and also from PD. These patients were supported with a tailored training plan. At this time the dialysis assistant took a patient education role visiting all patients who expressed an interest in Home HD at home which included an assessment for the home environment. Home HD was also incorporated into the WKC pre dialysis DVD which is given to all patients in the pre dialysis clinic. Educational and awareness events are regularly carried out in all satellite dialysis units to discuss home dialysis with both staff and patients to ensure that patients are aware of this options should they wish to consider it.

In 2014 a service tender for Home HD services was completed.

In 2015 a team of enthusiastic nurses working in the Isle of Wight satellite unit took on the training of patients on the Isle of Wight supported by the main Home HD team in order to train patients closer to home.

During 2016 the Home HD team set about mapping the patient journey from decision to independence at home to ensure smooth transition for all patients, to streamline the information given and the subsequent support of a patient once home. All patients were also categorised via a traffic light system by level of complexity and support needed by patients and or carers to try and improve support. All standard operating procedures were also updated during 2016.

The WKC has continued to improve, innovate and educate believing strongly that the patients should be involved in this process. This has involved several educational events for patients and staff including camper van events where patients can come and see others dialysing on the home machine. A Dialysis Web app Called 'Myrenalcare' has also been developed in conjunction with the Home HD team to improve recording of dialysis sessions, real time review and improvement in patient support and care. The Home HD patients were the first to trial this and have been instrumental in its further development which we hope soon will be available for all dialysis patients.

#### **What was the outcome of your QI work?**

WKC now has one of the largest Home HD programmes in the world. To the best of our knowledge we have the shortest training times reported but continue to have very low training failure rates and excellent retention with transplantation being the reason for discontinuation of therapy in more than 60% of cases.

WKC has collected extensive biochemical data in Home HD patients using the Nxstage system One

evidencing adequate dialysis and achieving RA standards. Additional data has shown excellent safety, improved blood pressure control with a reduction in antihypertensive agents and a reduction in the use of anticoagulants during the dialysis sessions.

Individualised prescribing has become a key part of the Home HD Programme tailoring the dialysis prescription to fits the patients' life and medical condition. We believe that this is one of the many successes of the programme improving retention rates.

WKC has pushed the boundaries in Home HD managing complex patients at home and truly making Home HD a viable option for all patients that wish to choose it as their dialysis modality.

WKC has also supported extensive travel for Home HD patients using the Nxstage system, facilitating travel to many designations across Europe, America and New Zealand.

### **What impact have changes as a result of your work had on patient care?**

WKC feel that they can now truly offer Home HD as a dialysis modality to all patients regardless of age, complexity, housing or vascular access. This ensures that all of our patients have a choice. Through learning and development as the programme has evolved WKC has continued to improve the care for patients on Home HD, but feel there is constantly room for further quality improvement of our service.

### **What did you learn?**

As the first Centre outside of the USA to set up a home Programme using the Nxstage system One, and indeed our first Home HD patients for 10 years, there has been a lot of things we have learnt along the way.

The key points that we have learnt and would advise others on is:

- A designated training area for Home HD with capacity for respite and review is essential to maintain programme growth.
- A designated Home HD (or Home therapies) team is essential. The data from WKC suggest that no more than 20 patients per nurse but this should be reduced to 15 per nurse if they are also training patients.
- A clearly set out patient journey from expressing an interest to independent dialysis at home has be extremely helpful in ensuring smooth transition for patients.
- The importance of education and awareness for all patients and staff.
- Early engagement with the Trust and managers is essential to ensure programmes are set up and supported correctly with the appropriate business cases in place.
- Above all ensuring that patients are always at the centre of all that we do and sharing the learning with them has proved exceptionally valuable to the ongoing development of our service.

### **Describe the whole process in three words**

Inspiring, life changing and motivating

### **Author's name and contact details and any links for more information about your QI project**

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