

Support for shared and self care in HD units

The latest RenalPro survey looked at policies on training haemodialysis patients to care for themselves in the unit. Self care in the unit can be a stepping stone to home HD, but it can also allow patients who do not wish to dialyse at home to have a more flexible regime. Shared care extends the concept of self caring to patients who are not expected to be completely independent. In shared care, patients undertake those tasks related to HD that they feel comfortable with and can carry out safely with staff available to supervise them and carry out tasks that they cannot perform.

To support shared and self care staff need time to be trained themselves and time to train their patients. If turnover is not too high, eventually there will be patients who can connect and disconnect themselves allowing staff time to train new patients and trouble shoot difficult accesses during the busy times. But starting a shared care programme requires a significant investment of resources and commitment so support at national level and from the local decision makers is helpful, if not essential.

RenalPro members from Australia, Belgium, Bermuda, Canada, Cyprus, Germany, Greece, Italy, Lebanon, Malta, New Zealand, Saudi Arabia, Slovenia, South Africa, Spain, Sweden, Switzerland, The Netherlands, the UK and the USA shared information on their unit's policy and/or the support for shared and self care at national and local level.

For those units that are not practicing shared care but are considering it, it might be helpful to know that over a third of respondents (9/24) to the questionnaire on practice work in units that encourage all patients to participate in shared care. Most of the others do support patients who ask to share their care. Only 4 respondents said that their unit prefers the staff to manage centre-based HD.

No-one reported that shared care was discouraged at a national level though only 18% (5/28) units felt that support at national level helped them with resources like train-the-trainer study days. These units were in Belgium, New Zealand the UK and the USA. The UK Renal Registry plans to collect data on the numbers of patients offered, and participating in, shared care which probably explains why all but one of the UK units said they had strong support from senior staff. It was interesting that the four US units gave very different responses, probably reflecting the policies of the different dialysis suppliers.

About half of the units that support shared care also support self care in the unit for patients who want to be independent but don't want to dialyse at home. Only one had a dedicated self care unit, and most would not be able to offer more than three sessions per week. Hopefully this will change as evidence of the benefits of customising HD regimes increases.

Five respondents said their patients had no option for home HD, and two of these said that home HD was discouraged at national level. Of those who do offer home HD, more than half said that limited resources meant that patients had to wait for training.

Respondents from Belgium, New Zealand, the UK, and two of the four from the US, felt there was strong encouragement for home HD at national level that helped resource home training. Given the many benefits of home HD, it seems strange that it is not common for units everywhere to be given incentives to promote home HD and train patients as soon as possible.

New machines designed to make self care easier are coming onto the market. The NxStage is the first to be used widely and it has clearly increased availability and uptake of home HD. Marisa Pegoraro says that her hospital in Milano, Italy has re-introduced home HD after more than 20 years thanks to the use of this simple machine.

Thank you Marisa and everyone else who contributed information on their local and national policies.

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Here are a few pictures from our regional programme:



If anyone is interesting in implementing a shared care programme in their unit, the resources developed by Paul Laboi and colleagues in the Yorkshire and Humber Region of the UK make a good start and can be downloaded for free at <https://www.shareddialysis-care.org.uk/resources> .