

RENAL ASSOCIATION WORKING PARTY ON HOME HAEMODIALYSIS

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Background

Home haemodialysis (HD) was first available to patients with ESRD in the 1960s and quickly became the most common dialysis modality. Patients on home HD are responsible for their own treatment and to some extent their own health. It avoids travelling time to dialysis units (a generally unsatisfactory experience) and requires less support from specialist nursing staff. Observational data suggest that patient survival is superior on home HD compared to facility-based HD (1-3) and technique survival with home HD is higher than peritoneal dialysis (PD) (4), even after adjustments for patient selection and case-mix. The explanation for this improvement in outcomes is thought to be related to benefits derived from greater patient involvement in their healthcare, better adherence to their diet and fluid balance and superior solute clearances achieved through better dialysis schedules. However, home HD is a less expensive option than facility-based HD (5,6).

There has been growing interest in recent years in quotidian HD, defined as all forms of HD therapy with 5 or more prescribed sessions per week. Both short daily and nocturnal (long nightly) HD are most easily delivered at home; short daily HD may also be provided in-centre (7). Whilst evidence remains sparse, randomised trials have shown improvements in blood pressure control and left ventricular mass with both modalities (8,9), and phosphate control for nocturnal dialysis (9). Non-randomised data suggest additional improvements in a wide variety of measurements including nutritional status, quality of life and recovery time after each dialysis session (10-12), even in patients with high co-morbidity (7). Preliminary observational data suggest an improvement in survival (13). Many assume that dialysis modalities which provide good outcomes and improvement in a range of surrogate markers must be more expensive but economic analyses have demonstrated that both short daily and long nightly HD are cost effective when compared to facility-based HD (14-16).

A variety of changes have led to a significant decline in the use of home HD in the UK over the last 25 years. In the early era of dialysis (1960 – 1989), the majority of patients in the UK dialysed at home. PD became a major home treatment in the 1980s. Since 1982 the number of patients on home HD has declined and UK Renal Registry data show that only 1-2% of prevalent HD patients in this decade are on dialysis at home (17). Some of the factors leading to a decline in home HD are actually improvements in care and include: increased availability of facility-based dialysis, the development of PD, and the growing success of transplantation. These are to be welcomed. However, international comparisons demonstrate that the decline in use of home HD has not been universal (18). It is difficult to draw conclusions from international comparisons of different healthcare systems. However, there is also striking and unexplained variation in the use of home HD among renal units within the UK varying from 0 – 8.6% of dialysis patients (17). This practice variation suggests that clinical need or patient decision making is not the main driver and requires further investigation. Recent analyses have shown that improvements in patient education programmes can change the uptake of home based dialysis options (19-21). Healthcare policy in all four UK countries encourages the transfer of medical care closer to patients' homes and the "empowerment" of patients to care for themselves. In 2002, after an extensive review of the evidence on

clinical outcomes and a health economic analysis, the National Institute for Clinical Excellence (NICE) recommended that home HD should be made available to all dialysis patients as an option and suggested that up to 15% of all dialysis patients in the UK should be on home HD (22). Although the overall goal of promoting home HD was supported, the 15% target of prevalent dialysis patients being on home HD was rejected by the renal community.

In the past decade the UK renal community has made great efforts to expand live donor kidney transplantation. The approach was multi-faceted, persistent, and was led by the British Transplantation Society. These efforts have led to a quadrupling in live donor transplantation rates in the UK in a 10-year period. During the same time period there has been no significant expansion of home HD despite the positive recommendations contained within the NICE report. The Renal Association can learn from this success in increasing living donor renal transplantation and put similar efforts into the expansion of home HD. There is consensus that a pro-active multi-disciplinary effort is needed to analyse the difficulties in provision of home HD in the modern era and propose solutions that would benefit both patients and renal units. The Renal Association home haemodialysis working party was formed to work through this agenda and make recommendations for increasing access to home HD.

Renal Association home haemodialysis working party

The membership of the working party was designed to represent the entire multidisciplinary team involved in the provision of modern home HD techniques and members were recommended to the group by the Association of Renal Technologists, British Renal Society and Renal Association. The group met on two occasions on 22nd April 2009 and 1st October 2009 to discuss and address the following key issues:

- Advantages and disadvantages of home HD over facility HD and PD in the modern era
- Whether patient education about home HD has been inadequate and has restricted patients' choice of dialysis modality
- Explain the barriers to appropriate patients starting on home HD in the modern era
- Assess the clinical benefits of quotidian dialysis especially if delivered at home
- Increasing the number of HD patients treated at home

Advantages and disadvantages of home haemodialysis in the modern era

Patients will only choose home HD if they can identify the advantages of the therapy which outweigh any potential disadvantages. Those attracted to home HD would like control of their treatment, avoiding travel for facility HD and be able to follow a flexible

dialysis schedule, which includes the ability to increase treatment frequency and duration as well as alter the timing of dialysis sessions. The risk of hospital dependence is probably under-recognised and may become more common with the expansion of large, efficiently run HD facilities. Suitable patients should have a reliable vascular access (a tunnelled dual lumen catheter is acceptable), adequate accommodation and motivation for self care, the latter being the strongest driver of success. Availability of a carer during treatment may be deemed essential for many individuals. Quality of life, rehabilitation and patient satisfaction is higher with home HD than facility HD (9-14). Patients, clinical staff and healthcare commissioners are reassured by the knowledge that patient survival on home HD is probably better and certainly non-inferior to facility HD. (3, 13, 22-23). Health economists and commissioners will only wish to recommend the use of home HD if it is cost-effective and in the past have raised concerns about the initial capital cost of home conversions and the use of the HD equipment by a single patient. There are also the financial, social and occupational related costs arising from the more prolonged training period required for home HD, up to 2-3 months in many UK centres. By accounting for all of these factors the minimal payback time before home HD becomes more cost-effective than facility haemodialysis has been reported to be ≥ 14 months (5). Consequently home HD is usually not regarded as a practical option for patients with plans for a living donor renal transplant. Payments to both patients and the renal centres have been made in Australia for every patient commenced on either home HD or PD but this still allowed the overall cost of home dialysis to be kept below the cost of facility HD. In the UK some alternative incentive to promote home HD other than direct payments would be desirable.

Peritoneal dialysis has the advantages of achieving similar short-term patient survival rates to HD and having many of the above benefits of a home based therapy without the need for a prolonged training period or home conversion. However technique survival with PD is much lower than HD and the incidence of infectious complications, including peritonitis, has not improved significantly. The adequacy of PD in the absence of residual renal function and safety of long-term PD are significant concerns in the modern era and have raised questions about maintaining patients on PD for any longer than 3 - 4 years. The risk of encapsulating peritoneal sclerosis increases with the duration of exposure to PD and has been found to be $\sim 8\%$ after 4-5 years of PD (24). All of these considerations merit discussion with patients choosing a modality of renal replacement therapy (RRT).

Conclusion: An explanation of the clinical risks and benefits of each form of renal replacement therapy should be part of patient education in preparation for dialysis.

Patient choice and education

“Patient choice” is enshrined in the National Service Frameworks for the treatment of renal disease in England and Wales and by Quality Improvement Scotland (QIS). The unavailability of home HD in many units in the UK implies that it may not be offered during education about RRT modality options (17), although it is possible that some patients living in the catchment area of a unit that does not provide home haemodialysis are referred to a neighbouring unit that does. Failure of a significant proportion of patients with advanced chronic renal failure to opt for either living donor kidney transplantation or a home based dialysis modality has been shown to be partly related to inadequate patient education and limits in treatment choices offered. With this in mind many units now have patient education programmes run by specialist nursing staff with participation of patients on the various treatments. A randomised trial has shown that inadequate education before patients’ decide upon their preferred choice of modality of dialysis leads to a lower proportion of patients opting for home based therapy (25). To promote the uptake of home dialysis many units have adapted their patient education programme to put home or self care dialysis as the first preferred dialysis modality. With improvement in the pre-dialysis patient education programme at Manchester Royal Infirmary the proportion of HD patients treated at home increased from 9% in 2004/2005 to 14.2% in 2007/2008, which is comparable to the 13% rate reported in Australia. Patients changing from peritoneal dialysis should be informed about home HD as well as facility HD and patients with failing renal transplants should be also informed about all suitable forms of dialysis.

Conclusion: All pre-dialysis patients and those switching to a different renal replacement therapy should be educated about all dialysis options

Barriers to home haemodialysis in the modern era

a) Reduction in infrastructure and capacity for home HD

The proportion of prevalent HD patients on home HD has remained unchanged in the past 10 years despite the recommendation by NICE in 2002 that home HD should be expanded. The availability of alternative modalities of renal replacement therapy has

contributed to the reduction in the number of home HD patients from its peak of 2200 patients in 1982 to 430 patients in 2003, approximately 450 patients 2004-2006 and a small increase in patient numbers to 478 in 2007. Only 2.4% of all HD patients in the UK were treated at home at the end of 2007. This low uptake is explained in part by the availability of Automated Peritoneal Dialysis (APD), the expansion of satellite and centre HD nearer to patients' homes and the success of renal transplantation, especially pre-emptive transplantation and living donor transplantation (17). The prevalence of home HD in the UK is similar to France and Canada but is much lower than in Australia (13% of all HD patients) or New Zealand (25% of all HD patients) despite similar overall incidence rates (17,18). Within the UK there is still wide variation in the use of home HD among centres, regions and the home countries. For example at the end of 2007 there was only 1 patient reported to be on home HD in Northern Ireland (17). Interestingly some countries, such as Mexico or Hong Kong, have the majority of patients treated with peritoneal dialysis yet have no home based HD patients. Audit of home HD has not been part of the Annual Report of the UK Renal Registry because of the low number of patients in each centre.

Conclusion: The utilisation of home HD in the UK is at an historical low and a proactive increase in funding for machines, infrastructure and supplies will be needed to allow expansion of home HD.

b) Centre variation in home HD

Not all UK units provide home HD and, based on a review of the clinical-effectiveness and cost-effectiveness of home, satellite and hospital HD, NICE has recommended that the option of home HD should be available to all patients (22). NICE recommended that up to 15% of dialysis patients should be treated at home. Although this target is achieved in Australasia, very few centres in the UK have more than 5% of dialysis patients on home HD. However some centres which already have > 5% are expanding their numbers. It is believed that, with a skilled workforce and infrastructure, up to 20% of all dialysis patients could in future benefit from home HD.

Home HD may not be provided in every unit if the infrastructure costs of a home HD programme are perceived to be too high for the predicted number of local patients and so some patients may need to travel to a regional or sub-regional centre to pursue their choice to train for home HD if this is not provided in the local renal unit. The ideal national prevalence rate of home HD is not known but higher prevalence rates may be achieved by having a designated home HD training centre serving

several renal units within a region akin to current service provision for renal transplantation.

Conclusion: All renal units should provide home HD or develop links with a regional training centre

c) Patient selection

Traditionally many UK centres restricted home HD to patients with motivation, a helper and suitable accommodation i.e. “nous, spouse and house”. Patient demographics and expectations in the modern era may have contributed to the decline in home HD. The age and co-morbidity of the dialysis population is increasing whilst there are many socio-economic factors which may have a negative influence on the patient’s suitability for home HD; more single person households, greater population mobility, the need for the partner or spouse to remain in full time employment, lack of support from employers for time off for training, lower availability of suitable accommodation for rent from the local housing authority. In addition many patients may be concerned about the perceived complexity or prolonged training required for home HD or the set up and take down time required to perform HD at home. Facility HD patients find several aspects of home HD to be barriers to considering home therapy: burden on other members of the household, lack of confidence about self-cannulation and fear of a catastrophic event at home (26). Dislodgement of vascular access needles or catheters and disconnection of the haemodialysis lines should be very uncommon complications of HD and should be detected promptly if they do occur. Patients are at greater risk of exsanguination following dislodgement of the venous needle as the patient will continue to lose blood at the rate of the blood pump speed unless the venous pressure alarm is activated. Undetected blood loss from dislodged venous needles or lines has occurred despite asymmetric setting of the venous pressure alarms (27). Blood detect devices have been recommended to overcome staff and patients’ fear that major haemorrhage from dislodgement of a venous fistula needle or line may go undetected by the machine alarms (28). This risk is avoided by the use of single needle dialysis in daily nocturnal HD.

Some centres require (and most centres prefer) that a home HD patient has an unpaid helper – usually a family member – to assist with HD and maintain patient safety e.g. in case of symptomatic hypotension or venous needle dislodgement. In some centres patients who demonstrate cardiovascular stability or who use either

single needle vascular access (as in nocturnal haemodialysis) or a blood detect device are allowed to perform home HD alone. An alternative would be to use a paid helper for HD at home (assisted home HD) as practiced in the Netherlands.

Certain categories of dialysis patients may opt to switch to home HD. Clinical teams should consider home HD for patients on in-facility HD or PD who are failing to thrive, patients on in-facility HD or PD with poorly controlled hypertension or poor biochemical control (e.g. phosphate, inadequate dialysis dose), or in-facility HD patients with large intradialytic fluid gains and poor tolerance of high ultrafiltration rates. Offering home over hospital HD to patients assessed as able to perform dialysis at home should be determined by patient preference or medical need rather than cost.

Conclusion: Too large a proportion of dialysis patients are considered inappropriate for home HD which may be addressed by better patient education and less strict patient selection.

d) Patient training and support

Effective patient centred training in home HD and patient support after going home are essential components of a successful home HD programme. Each programme must be sensitive to individual pace of learning and patient needs. Tools to track patient learning and progress and a method of certification of patients at the end of training, can accelerate training times. Availability of step down and minimal care options can help further boost patient confidence. A dedicated multidisciplinary team of community staff (nurses, social worker, technician, dietician, psychologist, nephrologist) trained in self care dialysis should undertake holistic patient review and assessment regularly. Access to facility HD must be available when necessary.

A major challenge of home HD is the resource, time and expertise required to set up a training programme and maintain the patients treating themselves at home. "Burn out" may reflect inadequate support from under-developed home HD units. A helpline to technical, nursing and medical staff must be accessible to patients whilst on dialysis at home. Even the expert home patient may at times need help and support. The expertise and commitment of the community team can play a crucial role in sustaining growth of home HD and enhancing the patient experience of home HD.

Conclusion: Home HD needs to be made more attractive for patients and providers by using a combination of better patient training and support and innovation in home HD practices.

e) Inadequate clinical research on home HD

There has been inadequate clinical research and very few randomised trials of home HD. This lack of clinical evidence has created difficulty in making credible recommendations for improvements in either the quality or quantity of treatment. Lack of evidence should not be perceived as evidence for lack of benefit. The recent resurgence in home HD therapy has been stimulated by poor outcomes of existing dialysis modalities and the reported superior clinical outcomes and benefits of home HD. The practice and prescription of frequent HD is not well understood. The Frequent Haemodialysis Network randomised trials in progress in the USA have set a good example of the multi-centre research efforts that are required.

Conclusion: The NIH sponsored Frequent Haemodialysis Network trials should stimulate much needed further research to provide evidence based analysis of the clinical-effectiveness and cost-effectiveness of the different home HD therapies.

Benefits and burdens of quotidian haemodialysis

The most common quotidian dialysis modalities are short daily and nocturnal HD (every night) Both short daily and long nocturnal HD have been shown to increase weekly small solute clearances and reduce recovery time after dialysis (12). Small solute clearances in schedules of differing frequency and duration can be compared by calculating the standard Kt/V. A well-conducted systematic review of the literature up to 2006 (14 studies of small cohorts of daily HD patients) showed that health-related quality of life, nutritional status and erythropoietin requirements improved in some but not all studies whereas a reduction in serum phosphate concentrations was shown consistently in all studies of nocturnal daily HD (29). A randomised controlled trial of frequent nocturnal versus conventional HD in 52 patients showed a significant improvement in left ventricular mass but no improvement in quality of life (9). Survival of short daily HD patients was 2.3-10.9 years longer than centre HD patients, who were matched for age, gender, race and presence of diabetes, in an international study (30). The physiological advantages of using higher frequency HD were reported to improve patient survival rates to that of age-matched deceased donor renal transplant recipients (30). A recent USRDS study comparing frequent HD

patients with propensity score-matched control patients on thrice weekly HD has shown a significant reduction in all-cause mortality in nocturnal HD patients (hazard ratio = 0.36; confidence interval 0.22-0.61; $p=0.0001$) (31). Pauly et al recently have reported comparable survival rates in nocturnal HD and randomly matched deceased donor renal transplant recipients (32). Concerns about increasing the risk of vascular access-related complications on daily HD appear to be unfounded. Complications of vascular access were similar in the patients on daily and conventional HD in a URSDS study (31) and in a randomised trial comparing nocturnal and conventional HD (9).

The Frequent Haemodialysis Network randomised controlled trials have been conducted to provide an evidence base for the effect of increasing standard Kt/V by 50% in the daily and 133% in the nocturnal trial; reducing the ultrafiltration rate by 20% in the daily and > 200% in the nocturnal trials and increasing beta-2 microglobulin clearance by 67% in the nocturnal trial (33). Results are expected to be reported in 2010. Observational data on hard clinical outcomes such as patient and technique survival and hospitalisation rates is now becoming available from the International Quotidian Dialysis Registry [IQDR] (34). A questionnaire sent to all nephrology consultants and trainees in Scotland in 2008 showed that the majority of renal medical staff (67%) would choose to perform a daily form of extracorporeal renal replacement therapy.

It should be emphasised that home HD is currently the only practical way to allow increased frequency and/or duration of HD to improve quality of dialysis. In-facility quotidian HD is not cost effective and only becomes cost-neutral if the cost per session can be reduced by more than 30% (35). This can be achieved by avoiding high staffing costs by switching patients to home HD. A cost analysis of dialysis modalities in the UK concluded that the annual cost of provision of home HD was lower than peritoneal dialysis and significantly lower than facility HD (36). Recently the Payment by Results for Kidney Dialysis Project Group Report June 2009 (Department of Health) reported that the annual cost of home haemodialysis based on 4 sessions per week was £17264 compared with £18980 for CAPD, £21900 for APD and £22152 for satellite HD using reference cost submissions of 16 participating Trusts in the UK (37). Quotidian (short daily and nocturnal) and alternate day regimens are being increasingly utilised in most home HD programmes in the UK.

Conclusion The recognition of the clinical benefits of quotidian HD and cost-effective benefits of home HD should be combined to become an indication for an expansion of quotidian home HD.

Summary of Recommendations

The implementation of the following ten recommendations is needed to optimise the use of home haemodialysis in the UK

1. Patient education to allow patient choice of dialysis modality.

- a) High quality education should be available for all patients who are expected to require RRT to promote informed patient choice of dialysis modality.
- b) A proactive approach of considering **every** pre-dialysis patient for home dialysis is likely to give patients and their family members a greater understanding of these treatment options.
- c) Each centre should define streamlined referral pathways for failing PD, failing transplant and in-centre HD patients so that choice is also available to patients switching RRT modality.

2. Patient training and support programme.

- a) The Renal Association guideline on HD (www.renal.org) states that home HD should be available to all suitable and motivated patients (Guideline 9.1).
- b) All patients choosing home HD should commence training in an environment conducive to learning under the supervision of experienced trainers.
- c) Home HD patients and their carers require a high level of ongoing support to optimise medical management and prevent patient or carer “burn out”.

3. Expansion of quotidian home haemodialysis.

- a) Quotidian HD (daily short or daily nocturnal HD) can be provided much more easily on home HD than facility HD. Guideline 9.3 of the Renal Association HD guideline recommends that self-treatment at home is the most practical way to deliver daily short or daily nocturnal HD.

- b) The better patient outcomes reported in observational studies of frequent HD and the symptomatic benefits described by daily HD patients should encourage incident patients to opt for home HD and existing home HD patients to switch to more frequent HD at home.
- c) If PD is no longer possible a switch to (quotidian) home HD would be a logical treatment option for patients preferring home based care.
- d) Review of facility HD patients should include discussion of their dialysis schedules and advise on optimising dialysis delivery by adjusting frequency and time. Patients with a low likelihood of renal transplantation may wish to optimise the quality of dialysis by switching to daily HD.

4. Patient selection

- a) The criteria for selecting home HD patients should be less restrictive. Patients may be allowed to perform home HD alone if they use either single needle vascular access (as in nocturnal haemodialysis) or a blood detect device.
- b) The suitability of patients for home HD should be assessed on an individual basis and a decision agreed by the home HD multidisciplinary team.

5. Improvement in renal staff education on home dialysis.

- a) All members of the renal multi-disciplinary team should be informed about the benefits and burdens of home HD so that all patients can be educated on their most appropriate mode of RRT without bias or prejudice.
- b) Training in home HD should be an integrated component of the curriculum for dialysis education of all renal specialist trainees
- c) Training in home HD should form an important component of the training of specialist staff involved in patient education and choice of renal replacement therapy. Multi-professional dialysis staff rotating through training programmes may be an essential component of generating the future skilled workforce for this modality.
- d) A web based resource platform for sharing problems and solutions specific to home HD would provide a valuable exchange of knowledge and ideas within the renal community.

6. More attractive or innovative home conversions should be used.

- a) Many home conversions are very “clinical” and regarded as less than ideal by patients. As well as converting a spare bedroom or public room or using a Portakabin in the garden several other options may be used to provide suitable and pleasant accommodation for home HD e.g. conversion of a garage, conservatory or caravan, a home extension, a Scandinavian log cabin.
- b) New technology has been introduced for daily home HD which requires minimal adaptations to the home. In 2009 more than 3000 patients are using the NxStage system in the USA.

7. Financial incentives to promote home haemodialysis.

- a) Commissioners should support an expansion of home HD because of its clinical effectiveness and cost effectiveness in comparison with facility HD.
- b) Home HD may be considered for all patients who are anticipated to require HD for at least 1 year as home HD then becomes more cost-effective than facility HD.
- c) Defined pathways and instruments (such as implementation toolkits) are necessary for a more homogenous approach to commissioning of home HD.
- d) An indirect financial incentive is needed to allow renal units to develop a home HD programme e.g. equitable treatment tariffs for home and facility HD to compensate for the initial home conversion and training costs for home HD.

8. Audit of patients on home haemodialysis by UK Renal Registry.

- a) An annual national audit co-ordinated by the UK Renal Registry is needed, reporting the proportion of dialysis and proportion of HD patients on home HD as well as the number of home HD patients per million population to allow a clear presentation of the prevalence of home HD in each region. These analyses should, if possible, assign home HD patients to the centre whose catchment area they live in, as well as reporting prevalence rates based on the centre that supervises the patient’s treatment.
- b) Information about the dialysis schedules being used at home in various units will allow evaluation and comparison of patient outcomes on dialysis.

- c) Individual units should also be encouraged to undertake specific audit of their own programmes e.g. local audits to document pre-dialysis education and choice of home HD for all incident patients.

9. Update of NICE Technological Appraisal Guidance No 48.

The NICE 2002 recommendations on home HD should be updated (next update was due in August 2005). Several issues merit review:

- a) NICE guidance on target prevalence of home HD
- b) assessment of innovative technology which requires minimal home adaptation
- c) specification of standardised home conversion guidelines
- d) implications of the wider use of frequent and long HD schedules

10. Scientific research in home haemodialysis.

Clinical research on home HD is needed to evaluate the clinical-effectiveness and cost- effectiveness of home HD, especially quotidian HD.

Conclusion

Home HD offers the only practical means of providing an augmented HD therapy with flexible and individualised schedules. Home HD is cost-effective in comparison with facility HD. Better patient survival on home HD, adjusted for age, gender, overt co-morbidity and primary renal disease, has been reported in observational studies but a covert effect of patient selection and case-mix cannot be excluded. Given that home HD is a clinically-effective and cost-effective modality (lower cost and better patient outcomes), we should try to increase the proportion of renal replacement patients on home HD.

Implementation of the above recommendations should provide the basis for increasing the utility of home HD. The recommendations to improve local access and provision of home HD (recommendations 1-5) are more likely to be achieved if there are lead clinicians and lead nurses for home HD in each unit, who are given active support by clinical directors and adequate funding from commissioners. Improving the education and training of home HD for all clinical staff (recommendation 5) may be promoted by increasing the requirement for training in home HD within the

curriculum of renal trainees and including home HD in CME activities organised by the Renal Association, British Renal Society and sister organisations. The combined benefits arising from the development of new technology, innovative home conversions, comparable funding for home and facility HD, data reports from national and local audit and results of multi-centre research on home HD should also foster increased interest and use of home HD.

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